



Health and social care in the information society (VOIS)

Agenda for Research and Innovation

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Introduction

Sweden, like the rest of the developed countries, is struggling with rising healthcare costs due to changing demographics, a proportional rise of elderly people, dramatic rise in chronic illnesses and a major increase in mental health issues as well as increasing costs due to technology development. The World Health Organization, WHO, describes “health” as being “a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity”. Due to the importance of social factors in the health and wellbeing of individuals, solutions of health care problems limited to the healthcare system are no longer possible. Costs of treating chronic diseases continue to be the biggest challenge with more than 70% of the entire healthcare spending. This points to the need to prioritize investments that will help reduce the cost of treating chronic patients and other preventive measures.

Health care is in many ways facing a huge change. The individual and not the condition will become the centre of care. Individuals will be well informed about their conditions; will collect their own data via e.g. Internet of Things and will demand that the care-givers take this health data into account when making diagnoses. Via Personal Health Accounts they will be able to register their health data. Individuals will own their data, and decide how it should be used. This will enable a completely new eco system, with new actors, to grow next to traditional care. Results and quality in health and social care will be transparently presented and the individual will be able to choose the best care available. To be capable of producing good care for the proportional rise of elderly people, care will also, to greater extent than today, be produced abroad and in the home instead of hospitals. Many elderly people prefer to stay living in their own homes as long as possible, given that appropriate daily support and safe monitoring of health conditions can be provided. For the society, considerable cost savings can be achieved when elderly and patients can be treated at home, where there are relatives to support the elderly. For individuals improved life quality can be gained and for industry there is a huge market potential to supply services and equipment both to citizens and care givers. Current development in Smart Homes, Internet of Things and Mobile Health (mHealth) holds promises to offer appliances, systems and services that can significantly contribute to emerging innovations in tomorrow’s care and assisted living. All this will however put specific requirements on information management.

Health and social care sectors are some of the most information intense sectors of society and an effective information management between different levels and actors is crucial for individuals to be given good care. Well-developed IT solutions is a key support tool and information that is documented and managed within health and social care is a necessary and crucial resource in several aspects.

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Information technology solutions not only provide new possibilities but also need to consider privacy issues and patient integrity. Such issues are often affected by cultural differences. Mechanisms for regulating who can see what information and in what situations are a necessity from patient safety, integrity and also from work process perspectives. Without access to the right information at the right time medical personnel involved in the care of a patient may not make well informed decisions. There are several aspects of information management– including both work processes and information flow – which today have not been investigated enough and therefore not been developed.

In many ways Sweden is in a strong position as a research nation in health informatics. Generally, Sweden also has excellent fixed and mobile telecom networks which can be used for, among other things, advanced homecare. The ratio of inhabitants with access to Internet is among the highest in the world (89% 2012 – internetstatistik.se). Even so, 85% of individuals who are 75+, don't have access to the Internet in a practical way. In this case it is not necessarily the technical access that is the main cause, but it can be related to physical and, economical hindrances, complexity, computer problems, education etc.

Sweden is considered to be good at innovation and has been ranked as number one, together with Germany, Denmark and Finland, by the European Community 2012. What mostly drives innovation are SMEs and commercialisation of ideas, combined with an excellent research system, according to the EU report. Reduction of venture capital is tangible and negative though.

This agenda for research and innovation is produced with support from Vinnova's call "Strategic innovation areas-Agendas 2013-2015". Altogether, the process working with this agenda has been very interactive and useful. We have all learnt new perspectives from each other and in our work we have created a common vision and a strong commitment to join forces, on a national and neutral arena, to execute the vision.



Scenario 2030

In the 27th of May 2030 Linnea is born in Kiruna hospital. When she is newborn her parents and grandparents are asked if they allow that information, relevant for Linnea's medical records, is linked from their medical records to Linnea's. They accept linkage, as they think it is important that account can be taken in any hereditary diseases in Linnea's future contacts with health care. Linnea's medical record is therefore linked to medical records for her parents, her grandparents living in Vittangi and her grandparents living in Alicante in Spain.

During Linnea's childhood the family moves around to various locations in Sweden because of her parents' jobs. Linnea also has extensive contact with health services at the different places that they live, because she has problems with allergies and undergo several investigations. From a medical perspective, it is no problem with Linnea moving often, since her illness story follows her through her extensive medical records. It's just sad that she cannot build a personal relationship with a specific allergist.

In her teens Linnea secretly contacts a youth clinic to get contraceptive pills prescribed. At prescription the decision support system, in the pharmaceutical module of the patient records, discovers that Linnea's grandfather in Spain has had a blood clot ten years ago. Therefore it is inappropriate for Linnea to receive regular combined contraceptive pills. Linnea did not know that her grandfather has had a blood clot, only that he has had a hurting leg, and therefore she has not told the doctor at the youth clinic. After a discussion, Linnea gets a prescription of estrogen-free pills printed.

After high school, Linnea moves to Budapest for a year to work as a waitress in a cafe. During riding out, a serious riding accident happens to her, and she is unconsciously brought by ambulance to an emergency hospital. Paramedics successfully identify Linnea by an id app in her mobile phone, which they find in her pocket. After one of the ambulance drivers has transferred her identification information, data from her medical journal is transferred from Sweden to the ambulance. In the ambulance a warning in Hungarian is triggered that Linnea is allergic to certain standard drugs and the ambulance personnel also gets suggestions of an alternative medicine treatment Linnea tolerates. When Linnea is on her way in the ambulance, an emergency physician at the hospital starts to prepare the ambulance's arrival by reading through the information on what is known about Linnea's current health status. Emergency physician will also receive a background overview in Hungarian, adapted to the

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situation, from Linnea's extensive Swedish medical record. Since acute physician is well prepared when Linnea arrives in the hospital and can initiate relevant treatment directly, Linnea recovers relatively quickly.

Back home in Sweden, Linnea is asked if she wants to be part of a research study to investigate the possible causes of some allergies and evaluate a new class of allergy medications. Linnea is happy to do that, as she wants to be involved and contribute to fewer children in the future suffering from allergies. Any new medical studies of Linnea are not necessary, as the medical information that is needed can be read out directly from her medical record into the researchers' database. Scientists can also add information about where she lived, went to school and what special conditions that existed in those places, such as mold problems in buildings, from other databases. Linnea therefore only needs to answer a questionnaire about the restrictions she now feels due to her allergies.

The research study has been launched at an open-innovation-testbed linked to one of the university hospitals. This study was initiated by some university researchers who found a new compound that has shown to be very effective to allergies that have a particular reason but not to others.

In the study, both a major international pharmaceutical company, and a couple of smaller start-up companies that have developed innovative methods of diagnosis just for allergies, collaborates. Linked to the study are also a couple of the nation's most experienced clinically active allergists. The goal is to produce a so-called "theranostics" product consisting of a specific method of diagnosis and drugs for individualized treatment. Sweden with its coherent healthcare information chain and easy access to anonymized high quality patient data has become one of the leading countries at development of linked diagnostics and pharmaceuticals. This, combined with effective testbeds, where health care, industry and academia are working together, has led to that several global companies have set up innovation and development hubs in Sweden. An excellent track record from previous projects has made it easy to attract private capital into this allergy study.

When Linnea begins to study in Linköping, Linnea ends abruptly with her running training and her physical activity drops drastically. She continues to eat large portions of food and eating candy also increases significantly when studying. When she takes her university degree, she realizes that she has gained 10 kg in weight during the study period and that she should do something about it. Therefore she buys a membership to a privately operated Internet-based weight loss and fitness advisor, where she receives coaching on how she should do to lose weight by a computer-based coach. She also buys a scale which also measures body

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fat percentage in order to track her weight loss. She downloads an app to her mobile phone and buys and connects an ECG-equipment to her mobile phone to record her workouts.

The scale and the mobile phone are linked to her Personal Health Account, and from there fetched by her digital weight loss coach, so she can get personalized diet and exercise. Some days Linnea feels completely unmotivated to cook healthy food, but usually when ordering take-away, she uses a couple of restaurants cooperating with her weight loss coach, and cooking is adapted to Linnea's weight loss plan. Since Linnea feels that weight reduction is made on her terms, she is motivated and after six months she has reached her goal weight. Linnea has accepted that some of the information from her Personal Health account has been transferred to her medical record. When she a year later meets a physician for an assessment of an infected wound, she therefore is praised by the physician, that she by herself reduced her weight in a medically safe way.

This scenario illustrates only a few examples of the possibilities with an innovative integrated information change, supporting a number of solutions for decision support, home-care and patient-centred care. Such new services and products will lead to benefits for all, including patients, their relatives, innovators, industry and researchers. On the following pages, we will in this report describe a number of areas Sweden ought to focus on, to enable the above mentioned visions – and many more.



A coherent information chain

Health care and social services are getting more and more information-intensive with more opportunities both to produce information and to consume the produced information. There is a need for an information flow from the producers to the consumers that is complete and undistorted in order to enable all the people and applications that are involved in a person's health care and social services to both produce and consume information of relevance.

It is important to mention that this domain consists of many types of organizations and needs. For example, the care itself is today performed by a much more diverse range of care-givers than ever before, including private companies and organizations, municipalities and counties. Also non-profit organizations and Non-Governmental-Organizations are active in the care and support of the elderly, people with disabilities and other individuals with specific needs. Information will be produced, not only by health and social care, but also by the individual e.g. with sensors connected to mobile applications that can transfer information of importance and information supplied by the individual herself.

Information can be entered into health records in different ways, either in natural language, which is what care personnel are used to, or in a structured and standardized way, which might be harder to do. Natural language can be partially converted into structured information via NLP (natural language processing) but parts of the information could be lost or distorted. If information already from the beginning is entered standardized and structured it will be easier to analyse, but in some situations this is still a major challenge. A compromise, whereby information which will be used for analysis purposes will be entered in a structured form, is likely. Advanced writing tools can assist in the documentation process with advice on terminology and conceptual information models promoting standardization and semantic interoperability between care actors.

The increase in the amount of information will also escalate the need for the information to be sorted, analysed, and pre-processed by applications before a human can use it. Otherwise there is a serious risk for "information overload" with the human "drowning" in irrelevant and useless information. This requirement places greater demands on the transmitted information to be structured and well defined so it can be managed and "understood" by an application in a safe way without the support of initial human interpretation.

To support this increasingly information-intensive health care and social services, a coherent information chain needs to be created where all relevant information can be transferred from all producers to all consumers in a structured, well defined, complete, and undistorted manner.

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Portions of the information chain are already in place, but these are mainly the ones that are easy to create. They may involve transmitting certain information from some producers to some consumers in a non-comprehensive way. The information transmitted is also often unstructured so it only can be read and understood by a human, but not managed and "understood" by an application. Since a chain is not stronger than its weakest link, this means that the information cannot be utilized in an optimal manner.

The lack of a coherent information chain also means that those who create applications that produce or consume information also need to solve their information transfer by themselves. The threshold will therefore be higher for creating applications that produce or consume information than if the application could rely on an already existing coherent information chain for information transfer.

The coherent information chain principles - vision

- **Semantic Interoperability** – ability to exchange information between computer systems in such a way that the receiving system without manual intervention can interpret the information content and produce for the end user useful for participating organizations, processes and systems. This includes all health care providers such as county councils, municipalities, private providers and even the patient and, if necessary, the patient's relatives.
- **Quality assured** – Output data is reliable
- **Aggregation** – the ability to combine and use information from different sources
- **Intelligent views** – the ability to view the information whether it is text, graphics or photos, structured or unstructured in a way that is intuitive and easy to use
- **Contextualization** – the ability to view the information in its context and understand it so evidence-based decisions can be taken
- **Analytical** – the ability to identify trends and predict future needs and necessary actions
- **Ethics and information privacy** – the patient information is anonymous where possible, a correct level of integrity is applied to all levels of the care and research, depending on the needs of each point of care. The information exchange is absolutely secure in terms of both technical redundancy and encryption.
- **Useful** – Only relevant and useful data which can improve the situation of the individual and the society should be collected
- **Cost-effective** - Effective use of resources and optimal lead time
- **Reusable, exploitable and scalable** - the coherent information chain allows the integration of a wide variety of information sources and systems, to be used in many existing and future system, so that the data does not need to be manually transformed to fit into future applications. The information chain will also allow for new businesses, services and products in start-ups and existing companies.

Research is needed in this area to promote ONE coherent information chain and not as today, many diverging information chains.

The VOIS-agenda has found that if a coherent information chain could be implemented in Sweden, where most of the care information from private, municipality- and county-council-

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driven care organization could flow, a number of new possibilities for healthcare, social care, industry, innovators and researchers would open up. This would potentially lead to tangible improvements in care through a democratized evidence-based individualised care plan.

Examples of possible effects are:

- Better emphasize prevention
- Better information base for making informed decisions
- Provide opportunities for learning during the person's life
- Improved patient compliance (due to improved knowledge and information)
- Increased precision in diagnostic procedures (due to better and more extensive and complete information sets)
- Possibilities for new inventions, services and products, leading to new start-up companies and improvements in existing companies
- Possibility to monitor quality. Today information is fragmented and not possible to easily compile
- Improved healthcare research and education
- Sustainable reallocation of resources and strategic decisions
- Economic effectiveness

It must also be pointed out that it is important not to forget that it will open up for new possibilities which we yet don't know anything about as it is impossible to know today what information will be needed in future health and social care.

Unusually good possibilities in Sweden

The prerequisites to implement a coherent information chain are good in Sweden from a number of aspects.

Health informatics research in Sweden

Traditionally, Sweden has been one of the leading research nations in health informatics (HI), and in electronic health care records and documentation, both as a research area and as implementation in clinical care.

Swedish health informatics research and solutions have been spread to many other countries and a number of companies have also started. However, despite the good results in the past, Swedish health care today still suffers from a lack of well integrated information services and often the patients themselves, regardless of illness and mental capacity, who need to share information between different caregivers. Moreover, even within healthcare organizations staff is still forced to manually enter information that actually exists in other, but non-communicable, systems. The information is not automatically collected and transferred.



Social security numbers, National Quality Registries and Biobanks

The advantage of Sweden is that there is a rather high penetration of IT in health and social care, well-educated patients and professionals as well as proven ways to identify individual patients. A publicly funded health care, comprehensive and well-developed population health data and the recent advances in implementing quality registers and biobanks also place Sweden as a country where we rapidly could make use of this fragmented, but existing infrastructure. Swedes are also, by international comparison, generally positive towards their health information will be handled in computerized information systems. The social security numbers are a unique identification and have been given to every swede since 1947.

Sweden has 73 National Quality Registries which, linked to personal information, contain information about problems, diagnosis, treatments and outcomes. If there were semantic interoperability, a full exchange of information between health journals and quality registries record would be possible, and it would be possible to follow up on what was achieved in health care for all patients in the country in the speciality that the register covers. It would also be possible to monitor what outcome the individual counties, hospitals or clinics achieve. Quality registries could be used for several purposes, such as for long-term monitoring of the risks of drug therapy and for more individualized care where you could find out which patients would benefit from a certain treatment. The demands on industry to monitor the effects of their drugs or medical devices increases and the conditions that make such follow-up studies possible are especially good in Sweden, thanks to the registries.

However, there is still research and development work to be performed in order to utilize the full potential of quality registries. Information is often manually entered into the registries, sometimes information is entered by someone who hasn't met the patient and information is lost. Often information is not entered at all. All this means that you may not have the full picture when you need to track something. Quality data needs to be handled automatically and in a standardized way.

A bio bank is a collection of human biological material, such as blood samples drawn for clinical or research purposes. There are basically two types of bio banks: one is collected for research on a particular disease, the other is more general and should reflect the population in a given geographic area. We have a number of bio banks of high quality, such as PKU registry with a nationwide collection of blood samples taken from new-borns since the 1970s, and pathology archives containing 80 million paraffin blocks of tissue samples.



Make the information accessible for growth and innovation

As argued in previous sections Sweden has a competitive position from different viewpoints with respect to health informatics. However, it is not an obvious process how to develop this to the next higher level and make the required investments with the objective to enable involvements of individuals, innovation and industry growth. Data often needs to be collected in manual ways or is not easily available to researchers, innovators and industry. Furthermore, quality, privacy and security issues including anonymization still need special attention. But there is also a huge potential for improvements, innovation, clinical implementation of new products, processes or services in healthcare, if this vast amount of clinical data could be analysed and the results made available to the different stakeholders.

Some interesting projects and initiatives in this area are already going on in Sweden:

Open data - The opening of public sectors' databases for innovation, which has been a Vinnova focus for the last years, is very positive.

Inera's Service Platform (Tjänsteplattformen) is a national technology platform that aims to simplify for innovator and other companies to create new services linked to health data. Each service that would connect to the service platform follows the so-called Service contract, which specifies the technical framework for how the transfers of information must go between the various systems/services.

A good example is the current initiative to provide every Swedish citizen with a **Personal Health Account** (Apoteken service), which can be used to collect and store health-related information, but where the individual owns the data and have full access control. For exchange of information between the Personal Health Account and the caregivers' Electronic Health Record, a number of issues regarding semantic interoperability, export and import mechanisms and role-based access schemes need to be studied.

My care pathways (Mina vårdflöden) is a VINNOVA financed project (SLL/KI in collaboration with VGR and Skåne) with the vision to enable the patient to monitor their health online by providing them with access to history, the present and future events concerning their personal health feeds. The objectives of the project are to create new innovative inhabitant services for a mobile platform that enables patients to follow, own and manage their care and health situation, develop methods and business models that can encourage the formation of strategic alliances in which different companies / organizations interact and to create a Software Developer Kit (SDK) with online services for software developers which allows to design applications that are compatible with today's health

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information systems. The project is based on and also further develops the National Platform for eHealth services (<http://www.cehis.se/infrastruktur/tjanstepattform/>).

Stakeholders

Four main stakeholders have been identified in terms of who can benefit from the visions of the work suggested in this agenda. This broadens the scope when compared with today's situation. These stakeholders include:

- Health and social care organizations and decision makers
- Research
- Industry
- Individuals (citizens and patients)

Health and social care is maybe the most obvious stakeholder of an improved information chain, decision support and other services. As mentioned, health and social care, involve a lot of actors. This means that information exchange, decision support and other services need to take care of many different aspects, including a vast range of different information systems, which also can be mobile, and at the same time keep track of privacy, integrity and security issues. Furthermore it is expected that their IT systems have to adapt to future needs, expectations and prerequisites which in i turn will put new sets of requirements on information supply and principles. If such issues can be controlled and if information support can be tailored to support the needs of all these stakeholders, there is a strong possibility to improve patient care and safety, facilitate prevention as well as save money and time.

Research is also a very important field. Research projects are performed both within healthcare organisations and within universities, in many cases in an integrated set-up. Today many researchers within the field are using very limited data sets and seldom can test their ideas and solutions in real situations and environments.

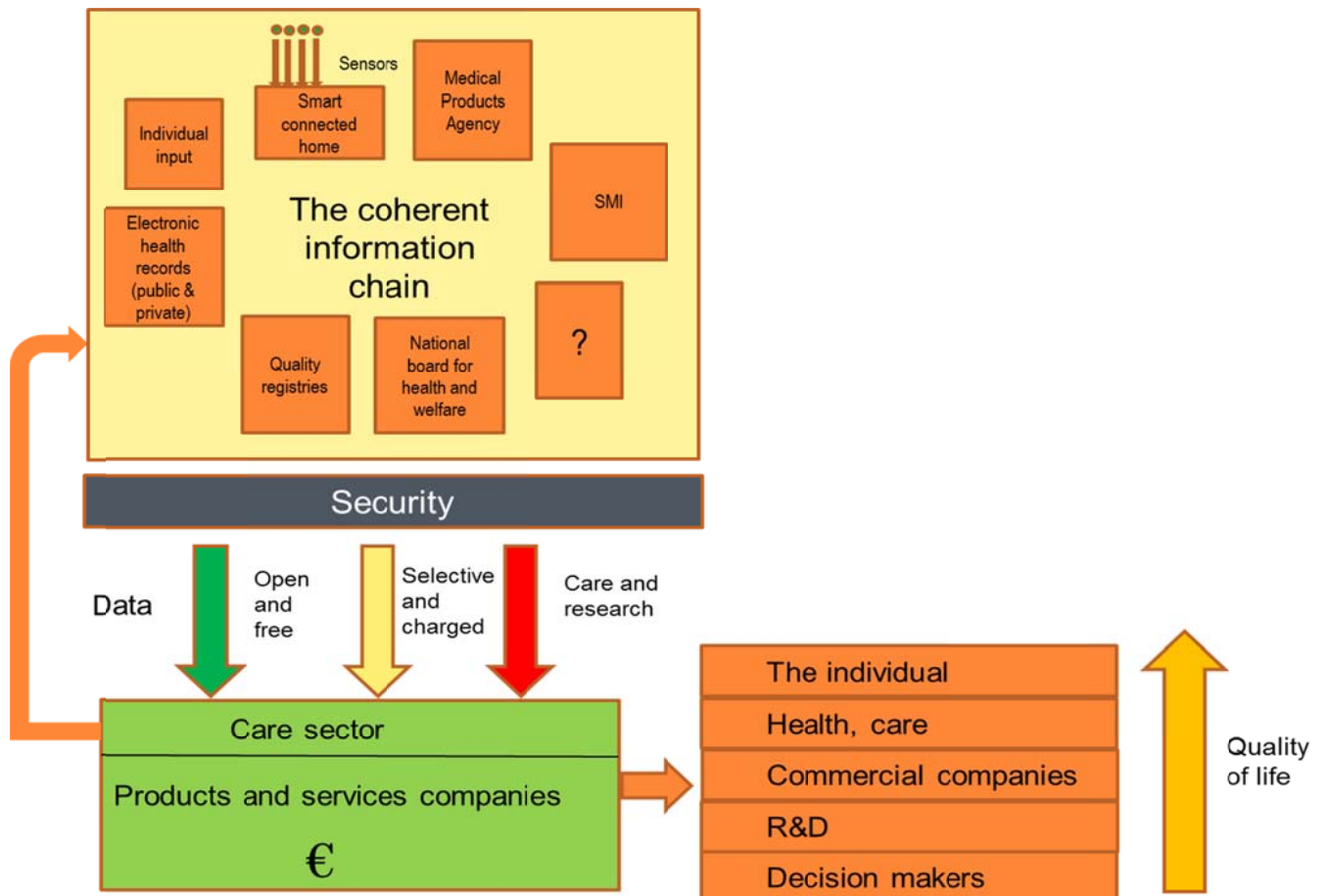
The possibility for **industry** to develop new solutions (services and products), test and evaluate them in real practice is today very limited. VOIS foresee a situation where both care providing organizations (incl. public or private) and researchers from universities collaborate in a more efficient way than before. This will lead to a situation where many more new services and products will be placed on to the market and can be implemented in real/normal care. Industry will also benefit of access to large anonymized data sets. The other way around is also possible – that industry has data which could be utilized by research and healthcare, for free or paid for.

Individuals i.e. patients, their relatives and persons that “only” need preventive measures would benefit the most if the research agenda suggested by VOIS will be a reality. In such a way, individuals would be able to receive tailored information to support preventive

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measures, receive a much better care when ill and at the same time keep their relatives informed and updated on the care and wellbeing of their family members.



VOIS vision is to utilize the data and applications available in health and social care to meet the requirements from the different stakeholders. The data possible to use should not only be limited to the data from health and social care. The digital footprint and mobile services (Google searches, information from food stores on what you buy, Runkeeper, Sleepcycle etc.) may also contain information possible to include in future applications. Research should look into the different possibilities to utilize this data from a broader perspective. Different sources of data could also be aggregated. The value of the combined data would be even higher.



Examples of how the Coherent Information Chain could be used

The coherent information chain will be used for a number of cases, both in direct care and for secondary purposes like decision support, clinical research, monitoring and evaluation.

We have chosen to elaborate on the areas “Smart, Connected Home”, with several challenges and research problems, and the area of decision support.

Decision support

Decision support spans a wide range of use cases. Not only clinical use where the decision support could be used to help to find a correct diagnosis or therapies, but also possibly web based systems, aiming to support a person to decide if he/she should go to hospital or not. Moreover, a decision support system could be used to help clinicians or care providers by highlighting the most relevant information in the electronic health record system, or support Swedish Institute for Communicable Disease Control (Smittskyddsinstitutet, SMI) in deciding when mass vaccination should be accomplished.

To implement knowledge is hard in the health and social care. It is proven that decisions are mostly based upon how you normally do and not on all available knowledge. One method to improve this situation is to make use of decision support tools, which take into account not only evidence based knowledge, but also knowledge from the patient.

We consider decision support to be one of the most interesting applications which can be built upon the coherent information chain, but decision support will not be able to be taken into clinical use without access to structured data which is readable for a machine without risk of misinterpretation. The quality of the input and the need for the coherent information chain cannot be emphasized enough.

Vision

Our vision is to create decision support models and systems that have the capability to analyse, sometimes massive amounts, of data that emanate from both structured and unstructured sources, which will lead to improved measures for prevention, diagnosis and treatment.

The new and developed decision support models will automatically adapt themselves to different stakeholders such as specialists, general practitioners, nurses and patients as well as to insurance companies, governments and educators. This means that the use of such systems will receive – just-in-time – support for many different types of decisions. Examples of such situations include:

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- Decision support systems that only activate themselves when needed
- The systems graphical and textual information will adapt automatically to the user preferences and way of working
- Automatic adaptation of the same support system for novices, triage nurses, general practitioners and specialists
- Seamless integration of the support system into any other electronic record or lab system
- Decision support that reduces the time for decisions and enables fast and more accurate decisions
- Automatic updating of the systems when new guidelines of research results are available
- Mobile support systems adapted to smart phones, tablets and other portable devices
- Effective allocation of resources and strategic prioritizations
- Innovative business models

Research need

To enable this new era of decision support, there is a need for research and development covering i.e. the following aspects:

- Different needs in different stakeholder groups
- Ethics – responsibility and liability in medical decision support systems
- Support systems that take into account patient specific data on the genetic, environmental, gender, age, and ethnicity levels, etc.
- Studies on implementation strategies for decision support
- Visualization and presentation models to suit different user categories
- Integration of Decision support into existing HIS, EHR and other health and social care record systems
- Innovative business and financial models
- Evaluation of the costs-effectiveness of the decisions and prioritizations

The smart, connected home

The coherent information chain is a prerequisite for the smart, connected Home. Both as a provider of information to the new, innovative services and for taking care of data from sensors and manually fed by the individual. Always on the individual's conditions in terms of needs, desires and privacy e.g. in terms of what sensors the individuals accept in their home.

The challenges and research problems related to care at home and assisted living are numerous and closely interlinked. They range from management of chronic diseases, infectious and neurodegenerative diseases to social isolation; reduced quality-of-life and increased dependence on relatives and societal care efforts. An obvious prerequisite to effectively cater to these challenges is increased and improved use of ICT support.

A vision for care and assisted living in the connected society

- Availability of an open, secure, reliable interoperable ICT infrastructure for networked sensors, communication equipment and information services in the home. An infrastructure which can be dynamically adapted to varying demands from users with respect to security, reliability and Quality of Service.

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- Effective support for semantic interoperability for sensor data, Electronic Health Records and Personal Health Records.
- Smart ICT services for citizens which support resilience and continuity with respect to degrading abilities and changes in health state for elderly.
- Effective service design with flexible technical solutions, which do not primarily assume today's technologies such as smartphones and tablets, but focus on function instead of devices.
- Support for mobility and social networks.
- Convenient support for planning, decision making and information exchange involving caregivers (including field personnel and also private vendors of services) patients, and relatives.
- Education and support for those who do not have the ability to use the new technologies due to different circumstances
- Payment and financial models to ensure the generic use of the services -

Research and activities needed

Much research in health informatics has been performed during the last decades, in Sweden and internationally. Many innovative technical trials, as well as practical parts of solutions, have been developed. Examples of interesting projects include InterCare (2000), Samba (2003), SAMS (2005), MobiSams (2006), VVP (2008), VIP-PA (2010), Old@Home (2005), TILLIT (2009), which all developed new ways to integrate and visualize care information. A common experience is that many successful research projects in this area have failed to transfer into regular use and to survive as established products on the market. This depends on a number of issues, including financial, organizational, technical, culture, use of standards and lack of testbeds, established cooperation, public procurement, difficulties to show Return-On-Innovation and lack of methodology to implement new ICT solutions in care organisations etc., but also due to the very fact that the medical professionals in general are conservative which is both good and bad.

This subject is also addressed in Vinnova report "Vårda idéerna" (2008) and "IT-implementering i vård och omsorg, Samspel mellan patientcentrerade vårdkoncept, teknik, ekonomi och juridik" (2007).

Organization of the health and social care

As health and social care in Sweden today is performed by private, municipality driven or county council driven care units, there is not one single unit which could decide upon a coherent information chain. The Swedish National Board for Health and Welfare can give some directives on how medical records should be transferred and stored, but not on a detailed level, as the county councils to a great extent are independent.

A project which has been successful in one county council seldom is taken into use at the national level, mainly because it is optimized for the prerequisites in a specific county and not reusable as a national system. Even within counties, information exchange between local care centres and the large hospitals is sometimes too complex due to organizational issues. In

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nursing homes the doctors might even have one system, depending on what organization he comes from, and the nurses another.

The organization with several care units also means that it is a fragmented market which meets the vendors of products and services for the health and social care sector. Combined with rigid rules and routines for public-sector procurement of innovative ICT-services, vendors might prioritize other customers, leading to less investment in products and services for health and social care.

The care sector is under big pressure and there is simply not time to take part in developing projects which, if implemented properly, would contribute to decrease the rise of healthcare cost. A lot of technical trials have been done and the care sector is, in some cases, tired of trials and wants to be sure that there is a commercial aspect and a real possibility to implement the result afterwards. If a care organisation takes part, they want to be able to buy and utilize the solution later on in order to improve the results in the organization. It is very important that the companies and innovators have the possibility to discuss with care sector and be able to learn about their needs and get feedback on solutions.

“Ädelreformen” was implemented in Sweden in 1992 and meant that municipalities got overall responsibility for long-term support, health and social care for the elderly and disabled. Municipalities took over some responsibilities which were previously on the county councils. Some county councils have implemented the reform and others will do it during 2013. In the case of healthcare knowledge, possibilities to take part in development projects and IT systems are in many cases not yet as accepted in municipalities as in the county councils. A prerequisite for good and safe care is that information can be exchanged between county councils and care providers. Development of information system and documentation is critical to ensure patient safety and good care.

Social care is often performed by private companies which should also be involved in development projects. But time frames of up to 15 years before a payback can be achieved often mean they are not interested. Care personnel usually work under hard stress and time limits, with a very varying competence background and with high staff turnover. There is also a need for the medical profession to accept that the care processes must often be coordinated with and subordinated to daily life. Introduction of ICT support must thus be integrated with organizational development. Education of users should not be forgotten when introducing new solutions and is a prerequisite for good results.

Either specific funding is needed to compensate private operators to take part in projects or demands for the private companies to take part in projects need to be taken into account in the procurement process.

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Lack of cooperation

The coherent information chain is a complicated area. Different stakeholders with different competences need to be involved. In many areas cooperation is not well enough established. VOIS recommend that completely new types of projects should be started, which would have a number of prerequisites, including that organising them in consortia consisting of at least one partner from each of the following : public care, private care, industry and research or, in other cases, public authorities such as National board of health and welfare (Socialstyrelsen), Medical Products Agency (Läkemedelsverket, MPA), Swedish Institute for Communicable Disease Control (Smittskyddsinstitutet, SMI) etc.

Smaller trials, included in the big picture, like decision support systems and arena for elderlies should be supported not only for the results achieved, but also for the different stakeholders to establish cooperation and gather strengths.

The small Swedish market

The Swedish market is small. There are too few citizens in Sweden to be able to finance the development of new products and services only targeting the Swedish market.

The innovation system has to support internationalization including support, with knowledge and financing, to adapt product and services to other markets. With support from the innovation system, use of international standards and access to the care sector, Swedish innovators developing niche products could reach a market outside of Sweden.

The innovating system however is fragmented. There are several incubators, possible financiers etc. and it is hard to get an overview. There is a lack of cooperation, a lot of projects are implemented and in many cases they are competing about the same end customer and the same financing instead of gathering strengths which is very important for a small country like Sweden.

As there will be too few people to care for too many patients in the long run, we will have to look at the possibilities on the European arena and also outside of Europe in some cases, to deliver care. Already today assessments of radiology images is, in some cases, being done outside Sweden e.g. in Australia and Spain. The maturity and awareness of the possibilities to perform care are not spread enough. The possibility to supply foreign care providers with the necessary information will be very important and will put specific demands on the coherent information chain.

Financial hindrances

A lot of good research is already done around the Coherent Information Chain, but few municipalities, county councils or commercial companies have had the economic strength to integrate the best parts into one functioning system

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Lack of persistence is a major problem. This goes for the companies who don't want to wait for the slow public procurement processes, the innovators might not have the financial muscle to wait and healthcare, in many cases, give up the project when financing has ended. In some cases the political majority could change with an immediate change in priorities. Financing of projects is often too short to see the real impact of an implemented result. Activities stimulating persistence are needed.

New business models

Effective business models for service vendors and care providers are needed. The design of technical solutions, must observe the need for market incentives and the special paying conditions for e.g. care at home solutions. There is often a distinction between who has to pay and who benefits from an investment. In many cases it is the public funding which pays irrespectively if the provider is public or private.

People with chronic conditions are good at taking care of themselves once they are diagnosed; e.g. by keeping track of your blood pressure serious complications could be avoided. The reimbursement system has been debated in the media during the last year but money is given for each visit NOT for keeping patients out of the hospital. There is no incitement for innovations in this area. A change is needed.

Maybe we have to look into having a new budget for preventive care and prioritize projects in this area? New innovative incitements influencing the individual to take better care of herself could be implemented.

The urbanization in Sweden might result in an overcapacity of specific competences in some areas where people are moving away from and a lack of competence where the population is rising. There is a need for new business models to support sharing of resources and also technical solutions to enable it.

There is also a need for new business models when making the information accessible for innovative services. What data could be used for free and what data is it possible to charge for? What data will only be available to research and healthcare and what data will be available to third-party developers. As the patient owns her own data, she might want to charge pharmaceutical companies when using her data but give it out for free for other purposes.

Culture

A number of technical solutions, including decision support and similar, are not implemented, due to lack of culture within the care to use innovative computer-based models. Already today, before the coherent information chain is realized, decision support system based on existing data could be implemented. Trials showing that decision support really works would be needed. Clinicians' today don't trust the systems as decisions taken in healthcare are really critical.

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How to measure success

It's hard to measure outcome in health and social care. Attempts to measure have been done for the last 10 years, but there is not a general agreement on how to do it in the best way.

Different aspects of success in this context could be measured.

- Indicators for international comparisons
- Return-on-investment
- Perceived quality of Health and social care
- Cost-effectiveness and economic efficiency

Recent research around Nordic eHealth indicators has been published and work on economic indicators is in progress. The goal with cooperation between researchers in the Nordic countries is to develop, test and assess a common set of indicators for monitoring eHealth availability, use, usability and impacts in the Nordic countries.

In many of the proposed implementations involving technical solutions, the outcome is mainly an enhanced quality of life, or well-being. It is thus difficult to assess the return-of-investment when the outcome is not monetary, and the soft values of well-being must be better quantified.

In a person-centered care context, patients own experience of the quality of health and social care is central. It is especially important to reliably measure the perceived quality of care, using questionnaires or interviews, in a reliable and systematic way. By developing methodology for implementing quality-assured measurement of quality parameters in terms of both health care innovations and existing health it is possible to verify that quality standards of service are met. It is also possible to control the work of the health service towards quality.

Two important steps should be performed before the actual measurements can be performed: (i) the development of a clear description of the system under test and (ii) identification of the most important quality characteristics of the system to be measured and tested against standards. After formalizing these two steps it is possible to make measurements. The steps below constitute a fundamental chain of events in order to measure "new" parameters such as success or quality, as identified by Emardson et al. [2012]

- Definition of the construct of interest
- Identification of measurement devices and techniques
- Assessment of the validity of the measurements
- Definition a reference to make measurements traceable
- Identify the scales of measurements.
- Assess the uncertainty of the measurements



Privacy and ethical issues

The main threat to the new opportunities effective information exchange and increased use of technology in care supplies, is that patients feel that their information is not sufficiently protected and in various ways want to enhance this. This can be done by blocking their data, which means the data may not be used neither for efficient care or research. Also other threats to the quality of care will arise if you do not take adequate account of privacy, is that the patient does not have confidence in that the data is protected and therefore doesn't tell everything to healthcare personnel. In the long run, perhaps the citizens avoid seeking care or completely lose confidence in the healthcare system. Research is needed around how individuals in Sweden consider this matter and what can be done to improve the current situation. This situation differs a lot between different cultures.

Ethical reviews are an important process to ensure a democratic society. However, we need to find routines to conduct them as efficiently and quickly as possible.

There is a need for all projects to focus on integrity, privacy and ethical aspects of healthcare information, to investigate both possibilities and challenges with a new type of integrated and coherent information chain. As an example regulatory and ethical issues today and when moving into new expectations and conditions in the future information society should be examined.

Directives

EU, national and regional directives and initiatives influence the solutions the care sector request in different ways. It is important that all implemented solutions are flexible enough to adapt to changing circumstances.

It must also be noted that there are EU directives and regulations that must be met before an information system is placed on the market. If the system, in any way, may have influence on the safety of the patient and the manufacturer labelling make it known that the product has a medical impact, it will be regarded as a medical device and therefore must follow the rules applied to medical devices in EU before it can be marketed. The US Food and Drug Administration also have rules and regulations before a product can be marketed. The regulations are set up to regard the patients for default products to be introduced.

Research should be performed on what the situation is today and what we can expect in the future.

Make the patient a partner in the care process

As mentioned, it is expected that individuals will play a much more active role in future scenarios. We will face co-production of health and care among individuals, patients, relatives and representatives from the healthcare systems or other types of organisations. Individuals are thus a target group with respect to both production and consumption of data. In addition we will meet expectations on better transparency and ability to

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control/manage all type of data that relate to us as individuals. With an increased maturity regarding use of IT products and services and with control of their own data, individuals will be empowered and capable to take initiatives among themselves – a kind of social innovation - to find solutions on problems of concern. An existing good example of this is the community Patients-like-me (www.patientslikeme.com) with an ever-increasing set of applications and services.

There are a number of successful examples of patient involvement, for example home dialysis, Homecare for children at Astrid Lindgren's hospital for children etc., which should be expanded into more areas. With less hospital beds in the future and the risk of infections while being in the hospital, among others, patients need to take more responsibility for their disease, and actively participate in the care.

There is a need, for training and increased awareness to prepare citizens for their new role in the information society.

Technical challenges

Even if a large number of technical problems already have been solved, there are still a big number of challenges.

Standards

International standards should be used for all applications in the coherent information chain. Then the information can more easily be transferred to and from other countries and applications developed in Sweden can be exported. New projects should only be accepted if they follow current standards. Public procurement could be used as an important tool to reach specific targets; an example is to impel the suppliers to follow certain standards and to take part in integrative development projects.

In some cases there are different standards covering the same area. There is a need to test the standards and revise them if necessary to be able to give a clear recommendation.

We also need to involve the health care professionals more in the development of international standards e.g. ISO, CEN, etc.

Design of interfaces to information base

Interfaces to a well-structured and quality assured base of health-related data and information will stimulate innovation and serve as a valuable asset for a wide variety of industry actors. If carefully designed, such a base of information will foster development of new products, applications and services targeting customers within the healthcare system as well as patients and individuals. It is also believed that new business sectors with new business models, roles and interests will be developed that cannot be foreseen today. Of special interest are value-added services where the basic value of the information base is further enhanced and interfaces/services at a higher level of abstraction emerge.

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Design of interfaces to the information base should meet requirements on security, integrity, transparency, regulations, business models, openness and continuous improvement.

Quality assurance of data

With the increased number of sensors monitoring our health status, the reliability of the output data is vital. Any deductions based on sensor data must take the uncertainty of the data into account. This includes both technical limitations of the sensors, as well as environmental effects and human errors from the user.

How to meet expectations on quality assurance of health-related data (also retro-prospectively) is an important area. Research around methods is needed. Examples are to include with the data what kind of sensor has been used and under what circumstances (rest, cycling etc) the measurement is taken, certify the product which feeds data into the system and methods how to know if the individual has measured correctly.

Security

Security includes a wide range of possible research areas:

- Access control of open/semi-open/closed data
- Questions of ownership of the data. Who will defend the individual if the data is misused?
- Robustness for smart homes. What is the probability that the connection disappears, and what actions are taken then?

Security should be possible to adapt to different situations depending on what the individual wants and what kind of data it is.

Testbeds

The assembly and management of a testbed, both related to informatics and real-life observations, is costly and impossible for small and medium sized enterprises, especially when testing their first product. To enable high quality testing, it is of outmost importance to make such testbeds available on a per usage cost. The financing of testbeds should therefore be financially supported by governmental funding, enabling discounted rates and enabling growth in SMEs.

Informatics

Today, research efforts within health care which touches upon information management (e.g. within health informatics, human-computer interaction, visualisation, linguistics etc.) have a large potential but the limitation of a good information infrastructure makes it inefficient and sometimes also difficult to conduct.

Difficulties in accessing test environments with real data as well as difficulties to integrate with existing information systems are a hinder for good research. Applied research is

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dependent on making evaluations in as real environments as possible in order to get good results that can also serve as a ground for innovation and further development of products, services and applications. A more developed platform for information technology will therefore provide a better ground for research within several disciplines.

Today many researchers within the field are using very limited data sets and seldom can test their ideas and solutions in real situations and environments. This is probably one of the reasons that a number of problems that already have been solved never have been implemented in real care or spread out to a wider usage. A new way to exchange and integrate healthcare information will open up for a much better implementation strategy, if proper testbeds are created, where industry, researchers and clinicians are collaborating. Further on, if researchers could get access to large clinical data sets from electronic medical record systems and similar, the possibility to develop much better algorithms for decision support, information gathering and analysis would most probably be improved. Such datasets should be automatically updated from the clinical data sources, but at the same time always only contain anonymous data.

VOIS also suggest that new research projects must use (or develop) testbeds where real patient data, real patient care and real care providers can collaborate to test, evaluate and refine all new solutions developed.

No one wants to be the first to test a new solution with real patients. Industry does not have access to real patient data or large data sets. Health informatics researchers are too rarely linked to real patient care. VOIS suggests that a number of new *semi-public testbeds* are set up, to allow also smaller companies and R & D groups to test their solutions with already existing real healthcare systems. Semi-public means that the data is not public, but can be used by any registered research, industry or care organization.

We also recommend opening up for new *integrative projects*, where new solutions to integrate existing health care systems could be developed and tested.

Testbeds in IT environments are especially costly due to the cost for depersonalizing large enough data sets to make them useful. It is also complicated by the fact that solutions might differ between the different systems form medical records.

In-real-life testbeds

Different types of "in-real-life testbeds" a.k.a. living labs to be used to test new or existing technologies in health care or home environments are being built in several locations in Sweden. Hospitals are dedicating a specific ward where the staff will be experienced with using and evaluating new technologies during real-life use. Other examples are especially equipped apartments where people "live" during a test period and use new or existing technologies to evaluate both the technique and its usability.

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These testbeds will be very helpful in getting feedback on products and services that are finalized or closed to finalized, and to see how different equipment work together. They are, however, less useful when it comes to evaluating technologies in early stages with prototypes that are not fully functioning and hence cannot be used in real life hospital environments with patients, or when the product is under strict secrecy or high risk for the patient or caregivers. These testbeds cannot test multiple products in parallel as it will affect the test results of each product. For these circumstances, VOIS suggests building a full scale usability lab where controlled tests can be performed in simulated care environments. Such a facility does not exist in Sweden today and will be a partner to medical technology manufacturers as well as caregivers in procurement processes.

Possible roles of The Swedish Research Institutes

According to the trade association Swedish Medtech, one of the medical industry's biggest challenges is to market and sell innovative products to healthcare providers. By creating creative, neutral environment where clients in the healthcare, who have the needs, can meet and interact with potential suppliers of solutions, and academy, bringing the latest research, innovative solutions will be stimulated and knowledge can be reused.

There is also a need for demonstrators which can be shown to the care sector, especially smaller units, which might not know everything that is available in terms of technology, and to procurers who need to get more knowledge about what there is to ask for.

E.g. Research Institutes in RISE, or a new virtual institute, are well positioned to participate in and manage such environments, as they represent unbiased expertise with no financial interest in the outcome of the procurement. Requirements and needs from health and social care can be matched against existing and potential products and services from commercial vendors, without complications from active business in subsequent contracts, creating opportunities to develop innovative solutions for the Swedish and international markets.

Such a role for institutes is supported by the availability of existing infrastructure for verification, testing and demonstration of solutions and the ability to systematically build up additional testbeds and testbed environments with the aim of also providing a neutral marketplace for innovation-friendly development. As an example of potential industry interest, the Industrial Partner Associations of Swedish ICT Research has recently initiated a special Advisory Council ("Verksamhetsråd") in the area of eHealth, which is also established as a business area at Swedish ICT.

Smart connected home using Internet of Things

Current development in technology for the Smart Home is driven by a large number of parameters as e.g. detailed energy consumption will be monitored and offered to others through open interfaces. Smart Homes also enables various sensor systems to be installed.

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These can in turn lead to even more information that can be used directly or for other demonstration or use case purposes.

The Smart Home aims for a basic secure and robust infrastructure both within the home and connecting to the outside world (e.g., servers on the internet). Closely linked to the concept of the Smart Home is the central idea of mobility, applied both within the home (in a broad sense) and external to the home in everyday situations.

Internet of Things, IoT, provides a paradigm for connecting single sensors and actuators as well as whole networks of wireless sensors which are attached to the Internet in a secure, flexible and efficient way. The nature of an IoT in a domestic setting gives rise to a number of specific challenges, including a reliable and secure infrastructure for care-related services, as well as privacy-preserving solutions and usability tuned to elderly and people with reduced cognitive, motoric and sensory abilities. The use in everyday surroundings also requires high ambitions regarding resource description and service discovery. Semantic interoperability, i.e. to provide representations that are usable for discovering what type of services specific sensor nodes provide and to interpret available data with respect to the current context, is a key enabling factor for successful care services at home.

For communication solutions and technical appliances to be used for care in the home, there are very strict regulations with respect to safety and security. In the future, however, it will be necessary to define such requirements in a more flexible way. For instance, the ICT infrastructure already available in the home should be possible to declare and upgrade with respect to requirements regarding safety, security, availability, traceability and quality of service. It is also expected that people will buy aids for the elderly and also biomedical equipment that can be used in conjunction with solutions provided by professional caregivers.

Digital inclusion of the elderly and improved usability of appliances and services

Decreasing cognitive, motoric and sensory abilities result in difficulties to manage and manoeuvre standard access terminals (computers, smart phones, interactive TV with remote controls, etc.). To reduce this problem, we anticipate enhanced man-machine-interfaces; a combination of improved service design and increased use of automated and semi-automated cooperating sensors. Since many patients or convalescents will receive care at home, there is a vast potential for development of commercial and consumer-oriented ICT-solutions, which can also be adapted and accepted for use in distributed care. This will serve the double purpose of reducing the cost for the society to provide the technical infrastructure for delivering smart care at home and at the same time simplify for user, by offering familiar and well-known support devices, rather than receiving completely new appliances.

An important approach to ensure the usability and acceptability of new solutions is to adopt a human-centred design, based on the continuous involvement of the end-users. The issue of

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users' involvement and participation should be considered as an appropriate means for reaching the definition of the user profile model. As collection of personal data associated to a specific user for the personalization of human computer interaction, the user profile is necessary for guaranteeing the usability and acceptability of any technologies. The design process consists of several activities based on analysis, observation, design and verification. According to this methodology, the involvement of the end users is assured all along the project duration, in order to put emphasis more on the quality of users' interaction and experience rather than on the pure functionalities and technology of the solution.

Mobile Health – mHealth

This is a rapidly emerging area of research and development, focusing on IT-supported healthcare using mobile solutions. The smart home of the future will thus be indistinguishable from a mobile everyday life. For elderly and disabled people, the ability to safely manage also outdoors is important for a good life. Many will spend a large part of their time in summer houses, maybe also abroad, which might lead to complicated care arrangements, which however can be significantly alleviated by clever use of ICT support. The area of mHealth also includes provision of distributed care in developing countries, with huge industry potential and possible synergies with solutions for Swedish elderly away from their ordinary homes. Some central areas of mHealth are distributed care of chronic diseases, support for self-care, security and monitoring systems, fall prevention and detection, availability of medical records everywhere and support for wellbeing, good nutrition and social networking. The regulatory demand must though be taken into account before placing on the market.

Social arena for elderly

Research on older people's health and quality of life is an important challenge in the light of the demographic changes where the proportion of older people is increasing in Sweden. Our social environment is of utmost importance, and while most people find a structure and presence among colleagues at work, the circumstances change when retiring. Addressing basic health and functional needs is important, but a salutogenic approach to health, considering participation and independence, is necessary for good life conditions and rehabilitation. As we wish to live longer, healthier, and in our own homes, the social environment must be dynamic and not rely solely on physical presence.

The vision with a social arena for elderly includes an online multiple user videoconferencing, where users can participate in small or larger groups. The interaction is video and audio, enabling free participation also for the physically disabled. It will enable interaction with their peers, or family, irrespective of distance. Scheduled appointments with their physician, with the addition of data from sensors and the possibility to instruct and evaluate the reliability of the sensor data are possible.

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The vision with a social arena for elderly is also a platform where a variety of services and interactive tools like puzzles, contact sites for elderly and tools for stimulating motion, like skiing in front of the TV, can easily be found. There is a need for investigation of prioritized services. Which services are of highest interest?

To enable the digital social arena, there must be a development of technical interfaces based on open specifications or international standards. New products and services can be developed and instantly communicate with the existing equipment.

International perspectives

Many international activities adjacent to our area are going on abroad. Some initiatives are based on the fact that healthcare alone accounts for only 10 - 25 percent of the variance in health over time. The remaining variance is, according to Institute for Alternative Futures, shaped by genetic factors (up to 30 percent), health behaviours (30 - 40 percent), social and economic factors (15 - 40 percent) and physical environmental factors (5 -10 percent).

a) Region of Southern Denmark (RSD) – “Shared care” which is addressing this subject.

<http://www.regionsyddanmark.dk/wm319357> . The goal of the program is to facilitate real-time communication among patients, physicians, pharmacists, mental health professionals and specialists so all parties have insight into patient care plans.

b) City of Rochester, NY, for many years benefited from relationship they had with Kodak, which contributed to an economically strong city. When Kodak moved out, the economy suffered dramatically. The city leaders of Rochester pulled together the universities, and the hospitals, and the grocer’s like Wegman’s - and came to the conclusion that the focus for Rochester should be healthy citizens. If they could improve the health of the citizens of Rochester, they could make the city one of the most attractive to live and work. As a result, Rochester went from being one of the least attractive cities in U.S. to one of the most attractive, with things like bike paths, new nutrition programs from universities, and Wegman’s innovative “Eat Well, Live Well” program.

(http://www.wegmans.com/webapp/wcs/stores/servlet/ProductDisplay?storeId=10052&partNumber=UNIVERSAL_37261)

Results: Healthcare costs in Rochester are about 20% lower than the national average thank to health education and wellness programs.

c) Camden Coalition of Healthcare Providers, NJ (CCHP), (<http://www.camdenhealth.org/>), works with healthcare providers, hospitals, and physician practices to improve the care and coordination of healthcare for Camden residents while decreasing costs. They have demonstrated that if they affect the small percentage of "superusers" of care with better, more coordinated care, they can increase the quality of care and decrease the cost to the system. For the past ten years, CCHP has done just that. By developing programs and

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working in conjunction with those on the front lines of healthcare delivery, they have reduced the amount of emergency department visits and inpatient stays for these patients. CCHP have identified “hot spots”; places with a high density of people with complex medical and behavioural needs; where there were individuals who were being repeatedly seen, and encountered recurring readmissions. The providers of food, called “Meals on wheels”, also call housing department to address social issues, such as mould etc. When all these were considered, it had a positive effect on overall health.

Results:

- Overall healthcare costs in the target population by 56.3%
- Emergency visits were reduced by 32.5%
- Inpatient visits were reduced by 56.5%

There is a need for projects looking specifically into what is happening abroad, especially in the Nordic countries as they are similar to Sweden in many ways.



How VOIS will strengthen the Swedish position

A major effort in VOIS is to use information technology to improve communication and coordination in order to achieve effective high-quality care. The goal is to understand the scope of public health problems, obtain accurate patient counts to best determine how people are being served and how many are underserved in some way. Another goal is to connect all the health care systems that come in contact with these patients in some way. Two key concepts here are communication and coordination – and they are at the centre of the VOIS. A third is community. VOIS is clearly not about any single entity or organization, but about the patients and the families being served. Just as it takes a village to raise a child, there is a sense here that it takes a community to keep one healthy. State-of-the-science data, information and communication support system for health care. That will include electronic health records, databases, Quality Registers, Biobanks, information technology systems and software, and, in some areas, enhanced and expanded telemedicine platforms and networks. This collaboration and sharing of medical information makes Sweden one of the few places in Europe, and one of the few places in the world, where "population-based" research can be accomplished.

The VOIS agenda includes a number of possibilities to strengthen the Swedish position.

- Growth of new companies thanks to new possibilities to access data both for testing and use in services
- Companies will be involved in building the coherent information chain
- Companies will be involved in building testbeds etc.
- A new market for secure services when accessing data
- Export of tested and approved mHealth solutions to developing countries
- Attracting foreign companies and supporting, existing and new, SMEs and companies with access to world class testbeds
- Implementing, evaluating and testing new solutions in health and social care will enhance the quality of life, and thus the working capacity of the Swedish population

The future life of the agenda

The VOIS agenda has been written during almost one year 2012-2013, summarizing the visions from a consortium of researchers, care providers and small and large enterprises. However, there is much more to say and to be investigated in this area. We consider this as an on-going work, which we have had the possibility to start through this agenda. After submission, VOIS will transfer to a forum on R&D to improve health care in the future.

Health and social care in the information society (VOIS)

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Managed by SP, the members of the VOIS vision will be invited to meetings, discussions, workshops and possibly national jams. Topics will include information and invitation to collaboration and mutual submission for research grants. It is also the intention to expand the VOIS-group, keeping it open to new members for the benefit of economic growth and enhanced quality of life in Sweden.

Future activities include:

- Forum for actions regarding applications for research funding, e.g. Vinnova SIO.
- Foresight as an in-built and on-going function of VOIS by engaging with projects like Future Agenda (<http://www.futureagenda.org/>).
- Share insight: Interact with other organisations and leading experts to better understand the future.
- Challenge assumptions: Be at the core of a unique global programme and debate the most significant topics for society.
- Inspire Change: Engage VOIS and others to tackle challenges and realize opportunity
- Exchange knowledge and expertise in core areas for eHealth or health informatics of today

The agenda will be revised as time changes, with an updated version always made public through SP, and will be used as reference for research plans, both national and international.

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