Innovation for a Sustainable Healthcare:
How can patients improve their own healthcare?

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MG101X Examensarbete inom Maskinteknik
Stockholm, Sverige 2013
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by

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Abstract

As the demographic pictures is changing across the Western world, healthcare costs are growing at unsustainable rates. In order to sustain the healthcare we’re used to in the Western world, new healthcare deliver strategies must be implemented. As the average person grows older, chronic diseases hit more people, requiring costly treatments for a growing part of the population. A successful approach could address the problem of medical adherence, together with increasing awareness among patients through increased involvement.

During the last century, the healthcare industry has received vast amounts of technological and medical innovations. However, the interaction between the patient and the doctor has very much remained the same. Is it possible that an increase in patient involvement can lead to improved healthcare outcomes? And further, how would they be able to become more involved? Through a qualitative study involving interviews with experts in the field, ideas were shared on how patient involvement can benefit both the patient and the healthcare, followed by how this involvement can take place.

Results involved the medical delivery strategy of P4 Medicine, closely related to the concept of Personalized Medicine. These theories advise the patients to take a much more active role in the healthcare. It encourages a shift from the reactive to the proactive healthcare, leading to a new view of the healthcare as a lifelong partner.

The conclusion drawn included that patient involvement is an important step towards a much cheaper and effective healthcare. With more data-mining and smarter systems, more people are able to develop services that can improve life for both patients and health professionals.
Preface

First of all I would like to thank my eminent supervisor, Zara Daghbashyan for her sharing of experience and ideas, and for her vital feedback throughout the whole project. I would also like to express gratitude to Nina Lundberg, a close friend of my family who both inspired me to choose this topic and provided important feedback. Lastly, I wish to thank my brother Yurij Gabassi for patiently helping me with the English grammar obstacles I encountered along the way.

This work is a result of my thesis within the subject “Globalization and sustainable development”, held at the department of Industrial Production at the Royal Institute of Technology in Stockholm, Sweden. Because of my interest in the way the Internet and other means of communication as well as new innovative concepts has helped globalization, I focused the study to see how patient involvement can improve healthcare services, particularly with the help of new technology.

Gianfranco Gabassi
Stockholm, May 2013
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1. Introduction

“The initial concept came to me when I was working at IBM on the PCjr. The day after the product was introduced, the Wall Street Journal declared the product a flop. After overcoming the initial disappointment, I thought, “if we knew what criteria people were going to use to judge the value of a product in advance, we could design the product to meet the criteria and ensure its success”. Trying to figure out how customers judge value and how to capture that information from customers in advance became my top priority” (Ulwick, 2005)

1.1 Background

A report published in October 2009 by Robert Kelley, vice president of healthcare analytics at Thomson Reuters, found that “The U.S. healthcare system wastes between $505 billion and $850 billion every year”. He also noted that: “Medical mistakes account for $50 billion to $100 billion in unnecessary spending each year, or 11 percent of the total.”

In May 2009, in an interview with National Public Radio, Peter Orszag, director of the White House Office Management and Budget concluded:

“Estimates suggest that as much as $700 billion a year in healthcare costs do not improve health outcomes. They occur because we pay for more care rather than better care. We need to be moving towards a system in which doctors and hospitals have incentives to provide the care that makes you better, rather than the care that just results in more tests and more days in [the] hospital.”

Similar arguments were conveyed in a 2011 report published by the Department of Information Society and Media at the European Commission, “Unlocking The Digital Future through Open Innovation: An Intellectual Approach”, stating:

It is without a doubt; healthcare in the member states is heading towards crises, an ageing population in relation to a decrease in financial resources and increasing costs of medical treatment require a structural shift in healthcare organization towards ICT enabled eHealth based on standardization and interoperability of electronic health records and equipment.”

Figure 1. Illustration of healthcare costs from 1960 to 2008

(New York Times, 2009)
During the same time, new innovation models have increased in popularity by both innovation scholars and managers. Organizations throughout governmental, public and private sectors, are all engaging heavily to understand how they can boost their innovation. The idea is to widen the company’s competence by collecting ideas and knowledge from outside. By using processes of patient involvement, new doors are opened to receive creative solutions from external partners, as well as giving people a feeling that they are part of the development. Before the Internet, companies were mostly limited to the innovation provided by their employees. Today, with a world that is more flat and information is available to a broader cast; we’ve made way for a new type of interaction that enables companies to be more innovative.

2. Purpose, Research Questions and Limitations

The purpose of this thesis is to examine ways that increase patient involvement to improve healthcare outcomes. By using processes of patient involvement, it’s possible for patients to become more active, which may lead to new healthcare methods by enabling innovators to receive faster feedback. It also gives patients a feeling that they are part of the development as well as the solution. I will further examine the possibilities and risks for conducting portals where external ideas may benefit the R&D process for the healthcare industry.

The different players in the healthcare sector all seek different improvements. According to a study made by Vincent K. Omachonu, the need, wants and expectations of the stakeholders can be divided into the following groups:

<table>
<thead>
<tr>
<th>Stake holders</th>
<th>Needs, wants and expectations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physicians and Other Care Givers</td>
<td>Improved clinical outcomes, improved diagnosis and treatment</td>
</tr>
<tr>
<td>Patients</td>
<td>Improved patients’ experience, improved physiological well-being, reduced waiting time, reduced delay</td>
</tr>
<tr>
<td>Organizations</td>
<td>Enhanced efficiency of internal operations, cost containment, increased productivity and quality and outcomes improvement</td>
</tr>
<tr>
<td>Innovator Companies</td>
<td>Profitability, improved outcomes</td>
</tr>
<tr>
<td>Regulatory Agencies</td>
<td>Reduced risks and improved patient safety</td>
</tr>
</tbody>
</table>

Furthermore, patients suffering from different diseases have diverse possibilities of being involved in their healthcare; I have therefore limited my research to patients with Parkinson’s disease.
Main question
How can Parkinson patients drive innovation, help the development and improvement of their healthcare?

Sub-questions
• What are the risks and possibilities for patients when helping the innovation of healthcare through their feedback?
• What are the risks and possibilities for the healthcare when patients are (through their feedback) helping innovation?
• What ways of communication can be used to increase patient involvement?

3. Methods

3.1 Qualitative study
For this thesis I will use a qualitative research method. Qualitative data analysis can include data from calls, interviews, observation notes and documents (diary, letter, newspaper and such). What characterizes the qualitative methods is the way data collection and analysis are made simultaneously and in correlation, and also the fact of the researcher trying to capture people’s handlings as well as the meanings of these handlings (the National Encyclopedia). The information will be gathered through interviews with three experts in this area.

3.1 Primary data
The primary data was gathered through three interviews. The participants are all working with innovation within healthcare, and some also pursue related research. One of the participants is both a researcher and a Parkinson’s patient. The primary data works as empirics in the study and shall be the foundation together with the theory, for the analysis and the conclusions that result from this work.

3.2 Secondary data
The secondary data for this work consists of research publications, literature, and web-based sources. The following search words have been used: healthcare innovation, Parkinson’s disease, personalized healthcare, combining medicines, innovation healthcare, patient involvement and P4 medicine.

What I’ve learned from earlier research is:
• Baldwin (2010) describes how entrepreneurial firms can use superior architectural knowledge to open up a technical system to gain strategic advantage.
• Kirk (2012) describes how America’s current health system is broken and needs a whole new approach such as the P4 Medicine strategy. It involves focusing a lot more on preventative care instead of only reactive care.
• Hoyer (2012) arguments that the openness and collaborative approach of open innovation, without a doubt leads towards the right direction for industry, governments and users. He describes how it creates a new approach to organize R&D processes within large and small organizations with private users.

• Hood & Galas (2008) find that new technology has enabled us to discuss new medicine delivery strategies, and that there are both technical and policy challenges when transforming the healthcare from preventive to reactive.

• Naraghi (2011) states that the growing prevalence of chronic diseases and aging populations around the globe are placing a heavy burden on the health system. He finds innovation paths to save costs by using more analytics and information technology.

• Von Hippel & Baldwin (2009) assess the economic viability of innovation by producers relative to two increasingly important alternative models: innovations by single user individuals or firms, and open collaborative innovation projects.

• Omachonu & Einspruch (2010) develop a conceptual framework, which articulates the intervening variables that drive innovation in healthcare. They argue that despite the stream of innovation and research on the art and science of healthcare, innovation has still been limited.

• Hitt et al, (2013) finds that the healthcare industry needs to change, and that current concepts of the patient experience are too narrow. They argue the future health providers will be viewed as partners in shaping health and wellness – a differentiated approach from today’s care that, according to them, is paternalistic, controlling and inconvenient.

• NEHI (2009) argue that patient medication adherence is a complex problem where no clear solution exists yet. An important question is to understand whether poor adherence can and should be addressed as a stand-alone issue or whether it’s best addressed by intensifying other health policy reforms. They conclude that a strong nationwide investment in health IT should have the effect of providing patients and clinicians with information they currently lack to devise appropriate drug regimens and provide adequate follow-up.

• Cottam & Leadbeater (2004) argue we need more distributed, collaborative and co-created solutions in healthcare. They believe in a new approach, called co-creation because a set of new relationships between users, workers and professionals lies at its heart. We set out this model. Many of the seeds of this new approach can be found within the current system. Communities of the kind we envisage are well developed in software and other fields.

• Bessant (2012) et al. finds that today’s funding models are not sufficient for the growing demand and expectations, and that the problem could be addressed by increased use of Web 2.0 interactive platforms.

• TNS Qual+ (2012) explores views on patient involvement in healthcare across fifteen European Member States. In-depth interviews were carried out with five healthcare practitioners and ten patients, in each country. The found large differences between regions on people’s overall opinion of National healthcare.
• Ulwick (2010) finds how using outcome-driven innovation can create breakthrough products and services.

### 3.3 Qualitative interview

#### Selection
The Snowball method has been used for selecting informants. It means that the researcher finds key informants, which in their turn can give information about new contacts. The criteria for being selected as an informant involved having work- or research related experience of innovation in healthcare.

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Occupation</th>
</tr>
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<tbody>
<tr>
<td>Respondent 1</td>
<td>Entrepreneur in Personalized Healthcare</td>
</tr>
<tr>
<td>Respondent 2</td>
<td>Ph.D. Researcher in Health Informatics and Parkinson-patient</td>
</tr>
<tr>
<td>Respondent 3</td>
<td>Ph.D. and Pharmaceutical Development Project Director at a large pharmaceutical company</td>
</tr>
</tbody>
</table>

*Fig 2. List of respondents*

#### Semi-structured interview
The interview guide (attachment nr.1) contains a list of six relatively open ended questions that served as a foundation for the interviews. A semi-structured interview style was chosen to let the interviewee express his or her thoughts and ideas, which may not have been covered by the questionnaire.

#### Interview ethics
As a researcher, you have responsibilities to your research participants and the people to whom you will present your findings. Starting points in considering ethical concerns are the four principles of Tom Beauchamp and Jim Childress (Patton & Cochran, 2002):

- Autonomy (respect the rights of the individual)
- Beneficence (doing good)
- Non-maleficence (not doing harm)
- Justice (particularly equity)

#### Transcription and data analysis
The interviews were recorded with the built-in microphone of the iPhone and then transcribed with the help of computer and text editor. The interview was analyzed and summarized to sort out relevant information that could help answering the research questions.
Interview guide

Qualitative methods generally aim to understand the experiences and attitudes of patients, the community or health care worker. These methods aim to answer questions about the ‘what’, ‘how’ or ‘why’ of a phenomenon rather than ‘how many’ or ‘how much’, which are answered by quantitative methods. (Michael Quinn Patton and Michael Cochran, 2002)

4. Theory

4.1 Innovation in healthcare

According to Omachonu & Einspruch, 2010, innovation can be defined as:

“The intentional introduction and application within a role, group, or organization, of ideas, processes, products or procedures, new to the relevant unit of adoption, designed to significantly benefit the individual, the group, or wider society. In line with this definition, innovation in healthcare organizations are typically new services, new ways of working and/or new technologies. From the patient’s point of view, the intended benefits are either improved health or reduced suffering due to illness. “

Chesbrough (2003) mentions that today’s world is faced with two new realities. The first is how the creation of new tools enables to reach beyond the conventional boundaries of the firm, allowing insights from users and customers. By allowing customers to use prototypes, vital information can be collected helping to erase flaws, misleading instructions or spot missing functionality, all before the product is brought to the market.

The second reality concerns the fact that people who are possible of contributing are distributed across the globe in many different institutions. Furthermore, many innovations span over different areas, forcing new models of innovation to find ways of leveraging the different knowledge resources of the contributors. The work involves people with other world perspectives, tools and methods foreign to those we’re familiar with, leading to feedback from many point of views.

In a report form 2002 by Wanless, heavy weight is put upon the role of the patient as a key architect in developing healthcare systems for the future. It highlights that increased access to information can help patient to be further involved in decisions of not only treatments but also prevention and management of illness. As patient involvement gains significance, the patient’s role moves beyond the “informed consent”. A report published by Cottam & Leadbeater in 2004, starts with:

“A wide range of prominent issues, including the environment, crime, and public health concerns such as smoking and obesity, cannot be adequately addressed by traditional services. Effective responses must encourage new norms of behavior within society, developing approaches in which those who use services become involved in their design and delivery. We need a radical transformation and a new approach: co-created services”.

The creation of this kind of services will involve mobilization of knowledge and
resources, enabling distribution to communities and encourage members to be actively engaged, different from centrally developed solutions. The co-design process leads towards customization, instead of trying to figure out a single design that fits all, rather working with diverse users and allowing configurations that bring their particular needs and wishes into consideration.

An example of the implementation of these ideas is the self-monitoring of blood glucose (SMBG), which today is an important part of managing diabetes. There are many types of blood glucose meters, however few are able to capture the patient’s data at home and, instantly and accurately sharing the information with healthcare teams for reviewing. A way of doing this could be to connect with different information platforms through standardized message formats and protocols.

Customer integration is feasible during earlier stages of the process, such as idea generation and conceptualization, as well as later stages, like development or prototyping. There is an obvious potential in mobilizing a wider community that includes patients and carers, to the ‘innovation front end’ in healthcare.

Currently, a lot of work is being done on standards for medical devices. It’s important to continue down that path, especially to accomplish open standards for how data is captured and communicated. With a flourishing innovation ecosystem, it would set an explosion of new players on the market that create value by taking use of the data in various new ways.

Other problems remain, as how this type of data should be regarded, and the related security and privacy issues. Bearing in mind the nature of the monitoring system and its task, it’s important that the system is stable to always be able to alert when a threshold has been reached. Devices submitting false evaluations cannot be left unchecked for weeks, ending in the hands of a patient that requires chronic care. The responsibility for this must be clearly assigned. Some may say it’ll be the provider of the ecosystem in which the solution is sold to hold liability and to categorize the services between regulated medical devices and consumer products, which also determines whether the application requires federal approval or not.

Although new technology can be beneficial, healthcare professionals sometimes meet it with reluctance, arguing about complicated user experiences and additional workload with no clear and measurable value (Innovahealth, 2012). The technology must therefore lead to improvements without adding workload on healthcare professionals. A more open, connected and robust health information technology environment is the key to expanding access, improving care and reducing healthcare costs (Innovahealth, 2012). The, usefulness of the health information found in the locked system silos today, need to be better understood, without forgetting security and privacy controls.

4.2 Patient involvement

In May 2012 the company TNS Qual+ at the request of the European Commission conducted a study on patient involvement. The aim of this research was to explore views on patient involvement in healthcare across fifteen European Member States. Some key conclusions made were:
• Poor understanding of the term “patient involvement”. Some thought it was the concept of the patient being responsible for his own health, others medical compliance and following doctors’ orders. Few thought it meant for patients to have a more interactive dialogue or opportunity for giving feedback.

• Concrete benefits of involvement in healthcare process were not clearly understood by either professionals or patients

• Communication is key for patient involvement. For patients it meant receiving explanations of diagnosis and treatment. For professionals, it meant patients describing their symptoms and progress of treatment. The main obstacle to effective communication was the time doctors spend with patients; both saying the time was insufficient to discuss treatment options.

• Patients described a feeling of a “traditional doctor-patient” relationship, meaning questioning the doctor wasn’t always welcomed. Patients found it easier to provide feedback with a more level arrangement, such as with nurses.

• Patients wanted a more balanced relationship in terms of information, however not being left responsible for decision-making, but freer to ask questions.

• Personal wanted choices such as ability to choose doctor, alternate treatments.

• Internet has been of great help to access information about symptoms and healthcare. Professionals had less appeal to this, seeing the risk of Internet misdiagnosis, which may be fixed by more regulated information.

• Patient involvement increased motivation and understanding among patients, leading to an increased conversation quality.

• Chronically ill patients had more experience of self-monitoring

• Younger patients and more educated question decisions more

• The requiring resources such as more time and staff

• A possible negative effect on the patient/doctor relationship.

• More explanation of options means an increased demand on doctor’s time

• Involving more input from patient, with the risk of it being inaccurate information from Internet, could mean patients disagree with the healthcare expert and avoid the best treatment.

• Eastern countries had less balanced relationship between doctors and patients, with less understanding of what patient involvement might include, and a higher reluctance of interacting with the health

4.3 The healthcare sector

The healthcare sector is worth more than $5.5 trillion, equivalent to 8% of the global economy. It’s an industry made up of very different players with separate interests. In general, there are five groups that can be identified:

• **Regulators** – ministry of health, committees that regulate guidelines

• **Providers** – doctors, nurses and other health professionals
• **Payers** – insurance companies, government agencies
• **Suppliers** – medical technology companies, pharmaceutical companies, scientific institutions. Involving anyone developing new products, treatments or doing related.
• **Patients** – the users and increasingly the knowledge base for their respective disorder

![Figure 3](image)

**Figure 3.** The group structures of the healthcare industry (Bessant et al, 2012).

The patient group stands for the largest part of the healthcare sector. Together with their relatives, friends, they hold on important information about medical treatments, services, devices that may result in more efficient processes and tools. Health suppliers and stakeholders have not been very interested of collecting patient’s thoughts and ideas, ignoring the case that patients can serve as a valuable knowledge resource. Increasing productivity in healthcare is one of the most significant determinants for the cost of delivering high-quality health care over the next 20 years. In order to accomplish higher productivity, four areas must be highlighted (Wanless, 2002):

• Better use of the skilled workforce
• Better use of IT
• More self-care by patients
• A redirecting of existing resources towards treatments that are cost-effective

The rapid increase in number of older people has extensive demands on our health system. In the US, chronic diseases accounted for over 75 % of the 2005 healthcare budget, and have been growing since. Hence, it’s come an attendant focus on the factors that can be modified to reduce the risk of such diseases. The promotion of exercise, healthy eating and smoking cessation has therefore risen up the health agenda. This situation forces consideration of individual choice alongside society's concern for improving the health of the population.

Recent facts tell a story about healthcare focusing more on diagnosis, rather than treatment and curement. In the book *Overdiagnosed*, H. Gilbert Welch (photo), with Lisa M. Schwartz, and Steven Woloshin, explains how lowering cutoffs can be a way of creating new patients. For example, an abnormality is claimed if the value found in a diagnosis happens to be above a certain cutoff score. The cutoff score itself is not something entirely scientifically defined, potentially leading to an arbitrary between what is abnormal and normal.
The direction during recent years has been to set the cutoffs lower and lower, leading to a lowered threshold, which will dramatically increase the number of individuals who are labeled as sick. Finding more abnormalities and defining these abnormalities more and more as pathological enlarges the medical market, thus being incentivized by potential financial gains.

**Figure 4.** The cutoff levels of cholesterol are lowered, resulting in an increase of patients diagnosed with high cholesterol levels.

### 4.4 Personalized healthcare

In a report from 2007 published by The New England Healthcare Institute (NEHI) it’s estimated that over a third of the 2.4 trillion spent on healthcare in the U.S could be eliminated without reducing the quality of care. The overuse and misuse of medical services together with unnecessary practices are large reasons for this waste. NEHI noted that:

"One third to one half of all patients do not take their medications properly. Patients with chronic diseases – which affect more than half of all Americans – are particularly susceptible to spotty adherence practices that leave them vulnerable to otherwise unnecessary hospitalizations and additional medical risks."

Much thank to new technology such as approaches to diseases, measurement tools, visualization technologies and computational tools, a new medicine delivery strategy has evolved (Hood & Galas, 2008).

It is a unique understanding that, more than a system, science or technology; health is a lifelong experience and a state of being. This encourages the healthcare industry to replace the current reactive mode of medicine, where we wait until the patient is sick before responding, with the P4 Medicine delivery system, over the next 10-20 years. It denotes the care on being (Kirk, 2012):

- **Predictive** – Using tests to identify genetic abnormalities and molecular biomarkers for disease, resulting in patients being aware of their health risks.
and able to predict the effectiveness of preventive and treatment strategies at
the molecular level.

- **Preventive** - Identifying the main causes of diseases will result in treatments
  that block or slow their progression. Preventive therapies will be customized
to each patient, consequently being more effective, with fewer side effects.

- **Personalized** - Each individual’s genetic information and behavioral and
  environmental health data will be used to create a personalized health
  management plan, customized disease-prevention strategies and, if required,
  unique disease treatments and therapies.

- **Participative** - Patients’ lifetime healthcare journeys will be more satisfying,
effective, coordinated and convenient because they will be empowered with
the information and tools they need to take a more active role in their health.
They will work closely with their health-care providers to plan, manage and
achieve their health objectives.

A project called Camden Coalition, applied a new strategy where they increased
 collaboration and gave preventative treatment to the most costly patients in Camden,
NJ, one of the poorest cities in the U.S. An analysis of the town’s three health systems
found that:

- 80% of the costs were spent on 13 of the patients %
- 90% of the costs were spent on 20 of the patients %

Patients with severe diseases including heart diseases, drug addictions, asthma,
cancer, diabetes, and mental illnesses averaged 62 hospital-visits a month. After the
program the visits were reduced by 40%, resulting in costs-savings of 56% (Camden
Coalition of Healthcare Providers, 2013). Self-care programs like these encourage
patients to become more active in the role of their own care. It’s important these
systems are created to be easy, user-friendly and comfortable for patients.

By providing patients specific and detailed information about their health, it is
possible for patients to see a path toward a healthier behavior (Goetz, 2010). The
magazine Wired, of which he is the executive director, published an article showing
how blood test reports can be made differently, making it easier for patients to
interpret and to get a good overview of the situation, followed by tips on how to
improve their health.
Generally, patients spend less than one percent of their life in hospitals and clinics. This leads to unawareness of the patient’s health in between health meetings. An average patient will spend an average of 80 minutes on consultation with health professionals each year, leaving them 500,000 minutes a year on their own, free to make their own decisions (Hitt. et al, 2013). Patients with lower adherence may choose their own path, leading to daily bad decisions, and a less desired outcome of the disease. These facts are evidence for a need of a healthy ecosystem that promotes accessible, affordable and understandable products, solutions and services that can improve health outcomes.

4.4 Parkinson’s disease

What is Parkinson’s disease?

Parkinson’s disease (PD) is the name of the group of conditions also known as motor system disorders that lead to loss of dopamine-producing brain cells (National Institute of Neurological Disorders and Stroke, 2013). Dopamine sends signals to the part of your brain that controls movement, and lets your muscles move smoothly and do what you want them to do. Symptoms vary from patient to patient but according to the Parkinson’s disease Foundation, the major motor signs of Parkinson’s disease include:

- **Temor** of the hands, arms, legs, jaws and face
- **Bradykinesia** or slowness of movement
- **Rigidity** or stiffness of limbs and trunk
- **Postural instability** or impaired balance and coordination

As the Parkinson’s disease progresses slowly, the symptoms become more pronounced. Initially, tremor is the first symptom to notice and also the most common sign of the disease. As Parkinson’s affect muscles all through the body, it leads to difficulties of walking, talking, and shaking (tremor) may confront daily activities. People notice symptoms between the ages of 50 and 60 however; some people experience changes at an earlier stage.
What treatment is available?

There is currently no cure for Parkinson’s disease. Nonetheless, a variety of medications and therapies are available that successfully delay the commencement and development of motor symptoms. The medications increase the function of dopamine in the brain, which is done by replacing dopamine, mimicking dopamine or preventing the breakdown of dopamine, leading to a prolonging effect.

The most successful therapy for Parkinson’s is levodopa (Sinemet), but long-term treatment may lead to unpleasant side effects such as shortened response, painful cramps, and unintentional movements. Generally it’s prescribed together with another medicine called Carbidopa that prevents levodopa from being broken down before it reaches the brain. With Carbidopa, a lower levodopa dose is allowed, leading to reduced side effects.

For some patients, surgery and deep brain simulation (DBS) may help, where the surgeon implants electro nodes to stimulate parts of the brain controlling movement. Another method is the use of dopamine-producing cells developed from stem cells. Although it has great potential, more research is required for it to become of therapeutic value in the treatment of the disease.

Treatment methods including nutrition, exercise and physical training are also helpful at all stages of the disease, helping to maintain strength, mobility and independence.

4.6 The patient data law

The patient data law in Sweden (2008:355) was ruled on the 1st July 2008. The purpose of the law is to increase the patient security and protect sensitive information. With an interopereated record keeping, health care professionals have increased possibilities of finding information, helping them to perform good and safe treatments. The interopereated record keeping contains information of earlier visits, diagnoses, tests, patient fees etc.

Only the patient and the related personnel have the right to read the journal, and all information is protected against unauthorized insight and distribution. Every time someone reads the journal it is registered, making it possible to track subsequently who has read the journal. The caregiver has an obligation to control who reviews the information, and the patient holds the right to see who was reviewed the journal. Furthermore, the patient may block information, which can only be taken away in case of an emergency situation where the information may be critical. The idea is that the caregiver should be able to find the patient’s journal wherever you are, and for the patient to avoid repeating the health situation for each visit.

Rising voices from health professionals

A recent article in the Swedish magazine “Dagens Medicin”, published by four doctors, argue that the patient data law must be modernized and implemented in a better way, and that it currently leads to uncertainty among health professionals. The formulation in “4 kap 1 §” states:

“One who is working at a health care provider may take part of the documentation of a patient only if he or she is participating in the care of the patient or by other reasons needs the information for his or her work within healthcare.”
They claim that the legislators assumed it’s only one health care provider that examines and treats a disease, and that every disease or state can be treated separately. Since many patients have more than one disease, cooperation and coordination across caregiver boundaries are necessary. The law makes it difficult to follow through a case, pursue research or patient oriented quality management, things that are done to improve the patient’s situation. They therefore seek a uniform practice with possibilities of allowing exceptions in some cases.

5. Results

5.1 Interview I

Respondent 1 is a self-employed consultant, working with product and quality development in medical technology for over ten years. As a fan of healthcare innovation, he arranges a hackaton where people brainstorm and come up with solutions together, with technology like Arduino, sensor-based systems but even hardware. Regarding the risk for patients of being part of the development of new healthcare products and services, there is a risk because the medicine hasn’t actually been tested. Possibilities include a clinical benefit before the drug is actually approved.

Parkinson’s patients often eat six different medications a day, in six different combinations, six times a day. With sensor-based systems, you can optimize and get a hold of medication performance. It includes measuring movement and motor activity, to see how it correlates with different medicine combinations, amount of sleep, nutrition, exercise, and mode, leading to incredibly efficient studies. Smartphones, tablets and sensors provide a lot better tools for personal medication and customizing healthcare, to optimize the current medicines instead of only developing new ones. Also, with large amounts of data from different cases you could learn lessons from it.

This can also lead to risks of focusing too much on optimizing the current medication, which affects pharmaceutical companies that survive on new developing new medicines. It’s important for the pharmaceutical companies to change their business model. To be sustainable they need to switch from selling pills to result, and within that lays optimization. It’s important to improve efficiency as a whole, rather than just thinking about the substances and their effects. With access to the required data sets, we can truly benefit from working with systems and algorithms. It will be a kind of crowd sourced innovation process, where the patient becomes much more involved and gains more knowledge because of the way he is collecting data and realizes how things correlates.

Today the healthcare uses interviews; give the patients forms to fill in together with some tests. The future lays a lot more in the Smartphones. Sensor data and similar types of automatically generated information will be increasingly used, resulting in more objective ways of measurement. For a Parkinson patient a hidden sensor can be used under the watch to measure the shaking (tremor) in real time, which can be stored in a database together with medication data. You want as much information as possible to determine what can affect a disease. I believe you can get results already by using simple parameters like weight, how much you move (using a pedometer or gps) and then a sensor under the watch. Those are three simple devices each available
today, which would probably give a lot of relevant data to work with. With continuous measuring you collect data without any “gaps” in the test series.

Today, patients describe how they believe the medicine work and few patients use applications that collect that data. Even though the technology has existed for a while there is currently no system that connects the devices and automatically sends that information. We need better control of ourselves, to understand our system and ourselves. To keep track of, how does my weight and exercise relate to the symptoms of my disease? You get a clear view when you have these tools telling how your weight, or stress, affects your values. I firmly believe that IT systems can ease or remove quite a lot of the work in primary care.

5.2 Interview II

Respondent 2 has a PhD in health informatics and pursues research on new tools for patients to use. Regarding risk of patient involvement, participants in tests can be biased, thus have a difficulty to assert their opinion elsewhere. Patient involvement has the greatest potential in optimizing treatment, being able to go from population to individual. Any drug or treatment is developed, virtually in all diseases, based on populations, with a statistical analysis of the reasonableness of a particular case. Since the actual treatment is always for an individual, there’s always a risk/chance of getting an unexpected effect.

The possibilities of individual patients, if they could be involved, could be very large. I don’t think we’re presently conducting that type of innovation in drug development, because of regulatory reasons. Regulations in Sweden for how pharmaceutical companies may interact with patients are some of the strictest in the world, since they have a commercial interest in this. Anyone who has data, the owner, the one collecting the data, and has control of the information, whether it's words or numbers or whatever, has the power. It’s therefore important that the person has an opportunity to choose who can see that information.

The involvement of “the crowd” can be tricky. A risk for the pharmaceutical companies can be, if their treatments are expensive, and it’s proven possible to gain the same effect with another cheaper option. An example is the Duodopa-pump, a mechanical pump that continuously injects a resolved Parkinson medicine according to a dosage, into the duodenum. It’s fitted next to the stomach and enables the patient to have an even dosage-response correlation since you skip the nutrition process that normally strikes pills. By collecting information and optimizing the medication schedule, you can get a similar dosage-response correlation. Based on the hypothesis of optimizing treatment you could theoretically save 360 000 kr per patient per year.

The best way of communication for feedback is using Smartphones. Out of 8766 hours, Parkinson’s patients spend 1 hour every year in neurological care. The rest of the year’s 8765 hours are spent in self-care. I believe one could imagine a better exchange of information, to collect information from the rest of the year.

A way of optimizing the patient’s situation is to allow the patients to measure their own outcomes to improve themselves, and provide them the tools needed. The healthcare uses the quality register that helps them to optimize their processes. Their collected information during the year can then be brought into the quality register. It requires cooperation to build something together. Today, patients get
recommendations from the neurologist but the information isn’t compiled systematically and distributed for Parkinson so far.

Information that pharmaceutical industry might be interested in involves demographic data and more continuous treatment outcome data together with wanted and unwanted effects. There is a very exciting project called Cleo, Clinical Expert Operating System, it’s a large decision tree of history-taking, information of what has happened in the past of one’s life.

Sweden is currently building something called personal health account. It’s a massive project in which all citizens within a year will have their own health cloud where one can put their data such as vaccination records etc. The responsibility will not lie on the healthcare provider since it’s outside the healthcare, relieving it from the patient data law. Because of that, the health account gives us a whole new set of opportunities to perform data mining and analysis in way that was earlier regulated, and still securing that the health records are anonymous.

5.3 Interview III

Respondent 3 is a project director of the pharmaceutical development at a larger pharmaceutical company in Sweden. They value patient input, and work proactively to understand what patients think of their products, with use of patients insight studies about products, dosages methods, and other important things.

There’s a risk for patients to participate and try a drug that is not fully documented. However, history tells that the risk of unintended effects for them is very low; the design of the study minimizes that risk. Many of the drugs are developed for a wide group population, and sometimes we have niched products.

With biomarkers and diagnostics, we can measure how the patient will respond to the medicine. It’s called Personalized healthcare. Traditionally, pharmaceutics have been developing medicines according to “one fits all”. The future will involve more customized treatment for each patient, including dosage, how often you should take it and what biomarkers to measure with.

Participating in a clinical test is a possibility to get cured, and some patients are guaranteed continuous treatment with the tested drug. They also get the possibility to participate and give feedback during the product development. If there are any clinical benefits, given that it’s done in a secure way, it’s possible for the pharmaceutical companies to test the medicine at an earlier stage.

Risks of involving patients could be that humans not always do as they are told, leading to difficulties of interpreting data. Medicinal adherence is a large problem; we need to find solutions, interventions that influence the way patients take their medicine. Motivation and information is important, you need to feel a driving force and understand why.

We don’t have an open channel into the company; the interaction goes through healthcare providers and patient organizations. I don’t think it’s good or ethical for the patient to have a dialogue with the pharmaceutical companies. There are plans on building a communication chain where the patient’s blood pressure is uploaded to a smartphone application and a web interface. A doctor can then see whether the patient
reaches the treatment goal. However I don’t think that pharmaceutical companies will ever see that information considering the confidentiality.

We have applications where patients can fill in and keep track. Currently it’s for observation purposes of the patient, but in the future you can build the whole chain for operating purposes. I believe the optimization will occur within the healthcare system rather than within the pharmaceutical company. It’s partly due to the fact that all medicines aren’t sold by one company, but also on the business model.

Today in Sweden, companies are paid for each sold pill, but new business models are possible to emerge. For example, we could say, “we take care of all your diabetes patients regardless of the medicines they use, to secure that they reach their treatment goals”, and are then paid for each patient reaching its goal. Those business models exist in some places around the world, the patient must then keep more track on each patient.

I believe pharmaceutical companies are interested in how addressing the problem of adherence. Among Parkinson’s patients, and generally patients with diseases in the central nervous system, the adherence gets worsened as the disease progresses. I believe that can be more important than finding new medicines in that area. Not even the existing medication is used in a correct way to the sufficient extent. If you could diagnose Parkinson’s at an earlier stage than today it could lead to new medicines that may treat it in a whole new way.

6. Discussion

In effort to explain how patient empowerment can increase patient outcomes and lead to a sustainable healthcare, I performed a study involving three interviews and a large search work of journals, books and articles. The interviews were performed on the basis of understanding how patient involvement could lead to better healthcare products and services, including medicines. Because of the very regulated pharmaceutical industry, and the way those companies do business, such collaboration is not recommended.

Furthermore, it’s the collaboration between the healthcare and the patient that will lead way for the new personalized healthcare. The chosen interview guide was therefore somewhat inconsistent with the material in the theory.

Initially it was shown how increased patient involvement could be technically solved and its influence on shaping tomorrow’s healthcare. The benefits for patient with increasing involvement in healthcare were primarily the ability to raise the patient’s awareness on how he can improve his own health. This was backed by (TNS Qual+, 2012), concluding that more involvement increased motivation, leading to an improved dialogue between the patient and the doctor.

By combining the more active self-care with monitoring systems, which enables the information to be reviewed by a healthcare professional, the use of patient’s health records will reach new levels of utilization rates. For example, with predictive care, medicines can be customized to ensure a desired outcome (Kirk, 2012).

For Parkinson’s patients who often eat six different medicines, 6 times a day in 6 various combinations, optimization has a lot to offer. The effect of expensive treatments such as the Duodopa pump can be gained through optimizing medication. By keeping track of your other values, Parkinson’s patients may understand how
exercise correlates with improved health values. Finding the right combination of medicines

The risk for patients involved a possible worsened relation with doctor, when they get more influence of the situation. The increased influence can be a risk if it turns out that the patient has misunderstood the situation, thus ignoring important advises. The risk of being misled is a further incentive for the healthcare sector to increase communication with patients. With a direct channel to healthcare professionals, patients could get secure and customized medical advice, all in one click. It’s not sustainable to let patients rely on such as short time of interaction with the healthcare every year.

The healthcare sector can benefit from patient involvement from various ways including optimizing care for the patient, which can severely reduce medical waste. With patients taking more control of their lives and becoming more aware, the problem of medical adherence can be addressed, leading to significant cost savings. Programs that monitor the patient can also send a reminder when the patient has forgotten to eat his medicine.

With personal health accounts being developed, the healthcare providers get new opportunities of performing data-mining and developing services that can improve life for professionals as well as patients. There is a definite need to clarify and communicate to improve patient engagement, as patients generally have a bad understanding of what the term actually means (TNS Qual+, 2012). For patients and doctors to collaborate, a common language is vital with clear terminology, including clear goals for what the activities related with patient engagement should lead to.

Tools that can help to improve the patient’s involvement are communication and information tools of different kinds including Smartphones, pads, and computers. A vital function is to be able to receive health information in a helpful way, as well as being able to understand what paths to take in order to improve the situation.

7. Conclusions

Bearing in mind the P4 Medicine delivery strategy, enabled by new technology, it’s difficult not to think how primary care will be in the future. After all, we are developing new systems and technologies that are able to collect billions of data points, for every patient.

This will clearly lead be different for each one of us. We may even predict diseases and suggest treatments that can minimize the breakthrough risk. It’s a future that will look back at the current system and conclude that the incentives were driven more by money than about health. As today’s health records are being uploaded on the cloud, we are breaking through the long era of having to pay for licenses when reaching medical records. IT providers like Siemens, have taken great use of the ownership of the data, charging anyone who is trying to gain access to that useful information.

Questions concerning regulations and privacy concerns must also be answered. As the law is right now, doctors have very limited possibilities of performing improvement work on their own. We must understand how to get future patients to realize the value of monitoring and tracking their progress, without making it a burden for their everyday life.
We are opening up for a future where we can together develop solutions to which there are no limits. People like game developers can take use of medical data to customize difficulty levels and settings, to ensure patients are encouraged to take ownership of the health.

We are reaching the understanding that we must continue to invest as a nation and together as a global community, to accomplish a deeper understanding of the biology of disease.
8. References

8.1 Published or printed references


8.2 Scientific papers


- Lapadat, J & Lindsay, A.C., 1999, *Transcription in research and practice: From standardization of technique to interpretive positionings*, Qualitative Inquiry, 5(1). 64–86

• Naraghi, M 2011, *Redefining Value in HealthCare: Innovating to expand access, improve quality reduce costs of care*, IBM Global Business Services


### 8.3 Internet-based sources


### 8.4 Pictures


9. Attachments

9.1 Interview questions

1. Could you please describe your role and job assignments, related to innovation in healthcare?

2. What risks do you see for patients when helping the development of healthcare?

3. What possibilities do you see for patients when helping the development of healthcare?

4. What possibilities do you see for the pharmaceutical companies when patients are involved in the development of new healthcare products and services?

5. What risks do you see for the pharmaceutical companies they are involved in the development of new healthcare products and services?

6. What means of communication do you think are suitable for patients to give feedback to healthcare?

7. What kind of information do you think that pharmaceutical companies would be interested in?