PRECISION MEDICINE
the future of data-driven healthcare

MFA Interaction Design
Thesis Project
2014

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ABSTRACT

Precision Medicine: the future of data-driven healthcare is an interaction design master’s thesis project aimed at presenting a vision of how genomic and quantified data might be integrated into the Swedish public healthcare system.

Precision medicine is a disease taxonomy model that, instead of looking at organs and symptoms, it classifies disease by mechanism and molecular diagnosis. This approach to medicine will allow big data patterns to emerge and algorithms to be developed, which, in turn, will allow more predictive and precise decisions about one’s health to be made. Considering the rapid scientific advances in genomics and the vast adaptation of wearable technology and other quantified self applications, it is likely only a matter of time before this data will play a larger and more integrated role in public healthcare services.

Within the genomics and precision medicine research community there is a strong focus on technology advancement. There is less of a focus on understanding human needs and the overall experience of patients within a new model of medicine and how that will play out in reality.

This thesis focuses on a user-centered design process, examining patient health needs and desires. It also looks at the rise of genomic data and precision medicine. Ethnographic research has been conducted with people in the different Scandinavian countries, hearing their health stories first hand, both in relation to genomic data, quantified self data and overall health. Commonly used service design methods such as customer journey mappings, blueprinting and business model mapping have played a large role in shaping the experience of the concept.

Kolla Hälsa is a preventive and proactive healthcare system concept for the public healthcare system in Sweden. Its preventive healthcare kit is mailed to the user’s home, where the user provides a saliva sample that is mailed back to a lab for analysis. Two weeks later the results are available through a video call with a health coach. The health coach helps the user create achievable short term actionable steps and a longer term health plan. Subtle prompts and cues trigger actions, while the health coach provides feedback to reinforce positive behaviours. The target group is people between 20 and 40 years of age, with a particular focus on those who do not currently interact with
INTRODUCTION

BRINGING USER-CENTERED DESIGN TO PRECISION MEDICINE

Precision Medicine: the future of data driven healthcare is an interaction design master’s thesis project aimed at presenting a future vision of how genomic and quantified data might be integrated into the Swedish public healthcare system.

Many research institutions and medical facilities are moving towards a precision medicine model, such as the University of California San Francisco (UCSF). Precision medicine is a new model of medicine with a new disease taxonomy. Instead of looking at organs and symptoms it classifies disease by mechanism. The goal of precision medicine is to provide more timely, effective, targeted and preventive diagnoses and treatments, through cross-referencing patients’ personal histories with biological patterns (What is precision medicine?, 2013). Although research papers and discussions in the medical research community are depicting the roadmap of policy changes and biological discoveries ahead, a focus on the patient experience is lacking. Additionally, there is a big leap between what is possible today with the scientific data we have and the vision of where this could potentially go in the future. We are at an interesting point where design can motivate a user-centered design process on how to move forward with this new model of medicine.

The interest in the area has been driven by the desire for a user-centered design process to discover the needs and desires of people’s health for the future. Ethnographic research has been conducted with people in the different Scandinavian countries, hearing their health stories first hand, in relation to genomic data, quantified self data and overall health.

How might genomic and quantified self data play an integrated role in the health care service experience?
BACKGROUND

PERSONAL INTEREST

During my internship at IDEO in San Francisco (2013), I was introduced to the concept of precision medicine. Shortly thereafter, I purchased a 23andMe DNA test kit, and submitted a saliva sample. After receiving my 23andMe results, I have been reflecting on the role of this information in relation to my current and future health. Revealing the results was a mixture of anticipation, slight fear of discovering something life changing and feeling overwhelmed, yet excited by the vast amount of information. As a consequence of the U.S. Food and Drug Administration (FDA) suspending 23andMe from providing health related data interpretation, it has become clear that the way (direct-to-consumer) genetic data is handled needs to be reconsidered.
HISTORICAL BACKGROUND

The thesis topic intersects systems biology and genomics, the digital health revolution and consumer-driven healthcare.

Genomics driven medicine started with The Human Genome Project (HGP) founded in 1987 as an international collaborative research project with the goal of sequencing the 20,000-25,000 genes of human DNA. Upon its completion in 2003, it led to a proliferation of genomic research that medical institutions, pharmaceutical companies and startups utilize to further discover genetic patterns in diseases and to create targeted drugs ("Human Genome Project" n.d). The human genome project was a huge scientific achievement, but the possibilities it opens up are even more astounding.

One of these startups is 23andMe, which was founded in 2006. They provide a Direct-to-consumer (DTC) genetic test. DTC is a genetic test that is accessible directly to the consumer without having to go through a healthcare professional (What is direct-to-consumer, n.d). Their customer base dramatically increased when they dropped the price of a DNA test to $99 USD and in December 2013 they had 500,000 phenotyped customers (23andMe fact sheet, n.d.). From the 22nd of November 2013, the FDA has suspended 23andMe from providing health data interpretations to new customers, due to data inaccuracies, the risks of false negatives and the data interpretations leading to people making misinformed decisions (Gutierrez, 2013).

Genetic testing is not a new phenomena. Newborn genetic screening is mandatory and usually consists of a search for 30 core and 25 secondary disorders. The disorders are usually rare, but can potentially be treatable if caught early in life (What are the types of genetic tests, n.d). Other types of DNA testing include carrier testing, diagnostic testing, predictive and presymptomatic testing, prenatal testing, preimplantation testing, paternity testing, and forensic testing.

In the last couple of years there’s been a huge push towards digital health, especially in terms of online appointment booking, digital medical records, along with a drastic rise in wearable technology. From this, The Quantified Self movement has risen to collect daily life data inputs such as food consumed, environmental location, mood, blood oxygen levels and performance. Inputs are gathered from wearable devices such as Fitbit, Nike Fuelband or mobile applications (Quantified Self, 2013). These are generally used for self-tracking and not shared with a doctor. Some people, however, often share this information on social media platforms.

TIMELINE

1990  Human Genome Project Launched
2003  Human Genome Project Completed
2006  23andMe Founded
2010  Swedish LifeGene Founded
2012  23andMe price drops to $99
2012  UCSF launches Precision Medicine focus
2013  23andMe suspended by FDA
The goal of precision medicine is to provide more timely, effective, targeted and preventive diagnoses and treatments.
community on links between genetics, health, the environment and response to therapies.” (UCSF)

The example which is commonly used to explain how precision medicine works today is breast cancer. Scientists have found strong links between particular genes, called the BRCA genes and the susceptibility of breast cancer. They have also found a recurrent tumour gene, called HER2. Pharmaceutical companies have been able to develop drugs that target that specific tumour gene. These targeted drugs have a much higher success rate, although it may only be effective for 10% of the people diagnosed with breast cancer.

Tom Insel, director of the National Institute of Mental Health stated that “the NAS report focuses heavily on cancer, but the implications for research and diagnosis of mental illness are important. Depression, schizophrenia, borderline personality disorder, and autism spectrum disorder are complex syndromes. It may be that many different disorders are embedded within each of these categories. The lesson from other areas of medicine is that a diagnosis that relies solely on manifest symptoms is not the best guide to choosing the most effective treatment. Precision medicine for mental disorders could be even more transformative than for cancer.” (Insel, 2011)

**DESIGN INTENT AND OBJECTIVES**

This project has been approached as a service design project, with the aim of addressing multiple touchpoints within the healthcare experience, with outcomes that are heavily influenced by user needs. The intent is not only to address how genomic and quantified self data might be integrated, but also how the system might be altered to provide a more pleasant healthcare experience.

In particular, a user-centered design approach has been used, with the goal of unearthing needs and opportunities as related to patient and health professional interactions. While medical doctors are an important group of health professionals, they are by no means the only healthcare practitioners users are in contact with. Nurses, pharmacists and, in the future, health coaches also have important roles to play. A user-centered design approach is important because it begins to uncover people’s healthcare fears and needs, rather than looking at how the system can be optimized.

**Desired Outcomes**

The desired outcomes of the project is a user-centered vision of future healthcare, taking into account a holistic and cordial service experience. More specifically, harnessing meaningful communication about genomic data, its interpretation and implications.
The project is situated within the Swedish healthcare system, predominantly because the project is conducted in Umeå, Sweden, utilizing local participants. Access to local users is a great benefit. Another reason is that the Swedish public health system model has many advantages over the complex medical system in the USA. Since the public health system in Sweden is equal for all residents and provided by the state, there is not the same vested interest of health insurance companies and pharmaceutical companies as there is in the US. This makes the Swedish health context slightly simpler to design for, as there are fewer authorities to consider, which means it is easier to put users first. For clarification I have lived in 5 countries, Norway, Sweden, Denmark, Canada and USA, and have experienced the medical system first hand in all of these locations (except the US).

Norway, Sweden and Denmark all have a fairly similar health system structure, but I have decided to just design for one country, Sweden. The diagram below explains the structure of the Swedish health system.
METHOD

SECONDARY RESEARCH METHOD

After speaking to a few healthcare practitioners, in assorted fields and levels, it became evident that there are not many of these professionals in the world who have heard of precision medicine and who are working towards the vision of this medical model. Since it is such a new area of research, there are only a few institutions which have embraced it, primarily UCSF and other institutions in the US. Because the concept of precision medicine is not established in Sweden, I have had to rely on journal articles and online talks, rather than speaking with people in person. This literature involves predominantly the book *The Language of Life: DNA and the Revolution in Personalized Medicine* by Francis S. Collins who led the human genome project and is the director of the National Institute of Health in the US. I also consulted more recent publications that addressed the upcoming challenges related to precision medicine, including a video recorded lecture series for the public introducing precision medicine by Keith Yamamoto, Vice Chancellor for Research, UCSF. A very influential paper was “Charting the course for genomic medicine from base pairs to bedside” by Green et al. where they explain in detail the steps needed for genomic medicine to become a reality.
ETHNOGRAPHIC RESEARCH METHOD

My primary focus has been on interviewing a broad range of people. These people can be divided into two groups: ‘patients’ and ‘practitioners’. The participants were recruited through my personal network and through contacts at Umeå University Hospital. Users were selected based on trying to find a broad range of people with different backgrounds, experiences, age and health concerns. The interviews were conducted in a casual setting without a script, and without taking photos or voice recordings. Instead, handwritten notes were taken. This was done so that the participants would be as open as possible in their responses and feel comfortable sharing personal stories. Names of ‘patient’ participants have been changed to protect their identity.

Healthcare Practitioners
The primary focus was on the patient facing doctors, especially general practitioners and doctors that have a background in genomics. I also spoke with two public health researchers investigating big picture epidemiology concerns, which is similar to genomics in terms of looking at big data. Most interviews took place over skype, while the three practitioners located in Umeå were conducted in person. The interviews ranged from 30 minutes to 2 hours, with most being about an hour.
**Patients**
The term patient is used to indicate the role of a person within the health system. In reality it means any resident. The length and deepness of interview varied from 20 min to 2 hours. The patients I spoke with were between the ages of 22 and 75, with a variety of health backgrounds. It was important to interview people at the different extremes to understand their various perspectives, needs and desires. Patients are subdivided into three groups: no contact with medical system (people who have not been to a doctor in several years); People who go maybe 1-3 times a year; and people who have chronic conditions and have constant contact with the medical system. The diagram, below, shows the people I’ve spoken with and where they fit in on the scale (all names have been changed).

Patients were asked questions geared towards how they view their health today, and what challenges they encounter. People who had been gene tested using 23andMe, were also asked how the genetic information has impacted their health decisions. With another group of participants the entry point was through primarily discussing the role of quantified data. In addition, time was spent listening to any stories that people wanted to share.

**Analysis & Concept Development**
Since this is a user-centered service design project, many of the typical service design methods such as persona creation, scenarios, customer journey mapping, blueprinting and creating a business model canvas were used. These methods are useful for better understanding how the different aspects of the experience could successfully and holistically merge.
TODAY’S HEALTHCARE IS SICKCARE

Today, disease classification is imprecise as it is classified by organs and symptoms. Doctors are merely mechanics that can fix you once you’re broken (Yamamoto, 2014). One interviewed healthcare practitioner discouraged preventive health check-ups and stated that people should only go to the doctor when they are sick, and that in Sweden there is a system in place for people at 40, 50 and 60 years of age to come in for a free checkup every 10 years. A Swedish public health researcher stated that, statistically, educated urban people go to the doctor more frequently with less severe and less developed symptoms, while uneducated rural people show up less frequently, with more severe and further developed conditions. Public health researchers spend a lot of time finding more effective ways of reaching out and educating people to get regular testing for certain conditions, so that people can get treated before it’s too late and even more costly. The diagram below indicates that today’s healthcare structure emphasizes sickcare, while preventive healthcare is largely neglected. The graph represents the USA, but is likely very similar in Sweden.

How might we move towards a healthcare system from a sickcare system?

What makes us healthy

- ACCESS TO CARE 10%
- GENETICS 20%
- ENVIRONMENT 20%
- HEALTHY BEHAVIOURS 50%

What we spend money on to keep us healthy

- MEDICAL SERVICES 88%
- OTHER 8%
- HEALTHY BEHAVIOURS 4%

*Source: Bipartisan Policy Center, Aug 2013
**THE RISE OF A NEW HEALTH PROFESSION**

Precision medicine introduces a new taxonomy of disease and aims to classify disease by mechanism. One disease state can have multiple, distinct molecular underpinnings, such as Diabetes Type 1 and Diabetes Type 2. On the other hand one mechanism may be implicated in more than one disease, such as cilia defects, retinal degeneration and kidney disease. Currently, scientists work in silos, meaning that researchers working on these different diseases are working separately although they are all working towards solving the same problem. UCSF is one institution which is shifting their whole focus on precision medicine and are trying to establish a layered knowledge network to stitch the silos together and utilize the knowledge more efficiently. *(Overview of Precision Medicine, 2014)* *(Insel, 2011)* Medicine needs to become more multi-disciplinary and in the future there might be a new kind of medical specialization emerging, with a focus on informatics and genomics *(Green et al, 2011)*. This means that the way medical staff is taught and how they practise medicine needs to change as well.

How might we create a new interdisciplinary health profession that addresses the needs of the modern patient?
GENOMICS ENABLES HEALTH DISCOVERY

A major thrust of precision medicine, involving a new disease taxonomy, is genome sequencing. Genome sequencing is not only necessary to build a medical research database and for furthering scientific discovery, it can also empower people to learn more about their own health. The benefit of utilizing genome sequencing is that DNA can contain the secrets of your future health and can predict your risk of getting certain health conditions such as diabetes, breast cancer, alzheimer’s and age-related macular degeneration. Because conditions can be predicted, many can also be prevented. 23andMe has highlighted many success stories where knowing results has helped users, among them Judy. Her story is below (23andMe Customer Gets Results, 2013). Although this may not be a typical result, there are some challenges in encouraging people to participate in genomic testing. A lot of the information around genomic testing uses words that sound big and complex. Big words that people don’t understand sound scary and people tend to avoid the whole situation. Another challenge is that most general practitioners know very little about genomics and are unable to guide their patients through the information.

How might we present genomic data that is useful and understandable?

Judy did a 23andMe test and brought her results to her doctor 2 weeks before scheduled surgery. They discovered that she carried a genetic variant that put her at risk for extended paralysis after general anaesthesia. The drug would need an unusually long time to wear off, and can even lead to her breathing stopping if the breathing tube is removed too early. Both her Judy and her doctor were glad she had discovered this, so they could take precautions during surgery.

PATIENT DRIVEN HEALTHCARE

Judy’s story illustrates anecdotally that people who have already been gene tested, here using 23andMe, have a vested interested in their own health. They are at the leading edge of an accelerating trend to actively promote their own health, rather than to passively rely on what their doctor says. E-patient Dave is a great example of someone who is advocating for patients to take more responsibility in participating in their health. The point he makes is that neither the patient nor the doctor should have sole responsibility; together they become a much more effective team (Let Patients Help Heal Health Care, 2014).

In the last couple of years the wearable technology market has dramatically increased. There are three main types of devices used for quantified self tracking: wearable devices such as Nike FuelBand or Fitbit; apps such as Nike+ or RunKeeper; and devices such as blood glucose monitors that can be plugged into phones. Dr. Jeffrey Olgin, from UCSF, developed an iphone application specifically to trace irregular behaviour in a patient with atrial fibrillation, in order to better understand her health patterns and, consequently, the causes. (The Age of Big Data, 2013) This rise in quantified self data is likely a response to people’s desire to know more about one’s own body and health. People often become engaged in quantified self applications because of its gamification. Another consideration is that qualified data can trigger timely cues and empower patients to engage and participate with their own health independently from healthcare practitioners.

How might we create a system that encourages patient participation?
ETHNOGRAPHIC INSIGHTS

Based on the ethnographic interviews with 20+ people I wrote down quotes that stood out to me. The quotes were all related to their own personal healthcare experiences, such as a challenge they have faced or ideas of how the healthcare system could be improved. The quotes were clustered into groups of similar findings and similar groups were pulled together to create a topic area, and the most interesting findings are presented in the chart below. (I had endless amounts of post it notes of quotes from interviews, as you can see on page 58-59 in the appendices). From the groupings I created an insight statement and a corresponding design opportunity. Each topic’s findings is presented with one quote from the patient’s perspective and one quote from the healthcare practitioner’s perspective, usually surfaced a tension or highlighting the core issue

<table>
<thead>
<tr>
<th>Patient Findings</th>
<th>Practitioner Findings</th>
<th>Insight</th>
<th>Opportunity</th>
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</thead>
<tbody>
<tr>
<td><strong>PREVENTION</strong></td>
<td></td>
<td>Preventable health measures benefit not only the system but the patient in the long run, yet people find out problems too late. Package genetic tests with a preventable health focus, and provide close follow-up, starting at a young age.</td>
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<td>“Fear of discovering something serious, but I’d rather know beforehand, I don’t want to die so early.”</td>
<td>“Hope to see a shift from burden of disease to preventative medicine measures. I’m a fan of exercise prescriptions.”</td>
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<td><strong>FAMILY HISTORY</strong></td>
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<td>Not all conditions are hereditary, assumptions could be dismissed or confirmed with the help of a genetic test. Combine family history with genomic data to empower people to make the right decisions.</td>
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<td>“My grandma had skin cancer, so I already know I’ll get that. I have fair skin so I burn easily, I know I should use more sunscreen.”</td>
<td>“In risk families with a strong family history of cancer we ask if they want genetic testing for cancer genes.”</td>
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<tr>
<td><strong>PATIENT UNDERSTANDING</strong></td>
<td></td>
<td>Information provided by doctors is often not communicated in an understandable language, without access to supplementary information. Provide an online patient portal with results and information given in understandable terms.</td>
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<tr>
<td>“The medical records are not really understandable to read, as a patient.”</td>
<td>“The medical chart is a legal document, so we use it for protecting ourselves and writing notes.”</td>
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<tr>
<td><strong>HEALTH PROVIDER RECORD SHARING</strong></td>
<td></td>
<td>Health records are rarely shared digitally, and the sharing only happens in one direction. Create a universal system which provides two way provider-to-provider sharing.</td>
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<tr>
<td>“Before leaving the hospital they printed a physical copy of the records, to take with me to go in an ambulance to a hospital in a different region.”</td>
<td>“Vaccine records are disconnected. Half the vaccines are through public health initiatives, and the rest through primary care.”</td>
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<tr>
<td><strong>CONFIDENTIALITY</strong></td>
<td></td>
<td>Due to confidentiality laws, health providers have little or no access to information that is critical for providing appropriate care. Divide medical records into sections that allows access to health information appropriate to the provider.</td>
<td></td>
</tr>
<tr>
<td>“Don’t mind sharing health info. Feel like I’d get better service if they knew more about my health.”</td>
<td>“We have to rely on the patient being able to communicate the information, otherwise we have no access to medical history or medications they are taking.”</td>
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<td></td>
</tr>
<tr>
<td>GENOMICS DATA</td>
<td>Patient Findings</td>
<td>Practitioner Findings</td>
<td>Insight</td>
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<tr>
<td>“I was expecting interesting results, like what would kill me, but I got just numbers that mean nothing to me. I want to know how to take action.”</td>
<td>“Most doctors don’t understand genetic data, and are scared of offering it to their patients.”</td>
<td>Neither doctors nor patients know what the genetic data means or what to do about it.</td>
<td>Through the guidance of a genetic counsellor provide actionable steps.</td>
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</tbody>
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<thead>
<tr>
<th>QUANTIFIED SELF DATA</th>
<th>Patient Findings</th>
<th>Practitioner Findings</th>
<th>Insight</th>
<th>Opportunity</th>
</tr>
</thead>
<tbody>
<tr>
<td>“If I had a doctor I would want to share all my data with them. I want them to have a complete picture of my health.”</td>
<td>“Would be helpful if at home glucose meters or blood pressure readings could be downloaded directly into the medical record.”</td>
<td>People are willing to share with the right people, as long as they know they get something in return.</td>
<td>Understand patients’ overall lifestyle through quantified self integration, and consistently provide health goals that are actionable.</td>
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<tr>
<th>HEALTH DATA</th>
<th>Patient Findings</th>
<th>Practitioner Findings</th>
<th>Insight</th>
<th>Opportunity</th>
</tr>
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<tbody>
<tr>
<td>In the hospital the Doctor asked why I was being scanned. I don’t remember the complex terms they use. Clearly the doctor did not read the medical record.</td>
<td>“Tracking a lot more data at every patient visit. BMI, Pain Scale, Depression screening, Smoking…”</td>
<td>The amount of data that needs to be tracked is increasing, but it is rare that they go back and look at the data.</td>
<td>Design medical records that allow for quick input and access to the most relevant data.</td>
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<tr>
<th>KEEPING HEALTHY</th>
<th>Patient Findings</th>
<th>Practitioner Findings</th>
<th>Insight</th>
<th>Opportunity</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I avoid going to the doctor; it’s inefficient, time consuming, and I don’t really trust them when they just keep on prescribing medication.”</td>
<td>“Often young people don’t think about death or illness. People usually start thinking about it when they have kids or if there is a strong family history.”</td>
<td>Healthy young people, especially, avoid the health system, but having regular check-ups can catch things much earlier.</td>
<td>A yearly at home test to measure actionable health parameters.</td>
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<tr>
<th>PATIENT PARTICIPATION</th>
<th>Patient Findings</th>
<th>Practitioner Findings</th>
<th>Insight</th>
<th>Opportunity</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I did a lot of internet research once I was diagnosed. I even found a DIY operation”</td>
<td>“Patients need a reliable source of medical info (not google) similarly to the up-to-date medical info for providers”</td>
<td>There is a desire for people to contribute and be more aware of their health, but they lack proper tools provided by health institutions (not google).</td>
<td>Provide tools that enable patients to actively participate, contribute and take responsibility for their own health.</td>
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</tbody>
</table>
Customer journeys are a commonly used service design method for mapping out both the current journey of a user throughout a system or service and the desired customer journey. The journey below is a generic journey of a patient going to the doctor. It is based on both ethnographic research and personal experience. A few aspects of the patient that I realized through this mapping was the following. Regardless of age, everyone first googles their symptoms, to see if it is serious enough to go to the doctor or to confirm their suspicion of what it might be. Waiting happens at very many points in the journey, such as waiting for the appointment, waiting in the waiting room for the appointment, waiting for lab results, waiting in the queue at the pharmacy and waiting for an appointment to see a specialist. By the time a patient gets to see a specialist half a year might have passed. Overall the experience of going to the doctor is not seen as a pleasant one, and many people both avoid and dread going to the doctor.
DOCTOR'S CONSULTATION

- Greet doctor
- Explain symptoms
- Answer questions
- Examine symptoms
- Say what I think it is

- Move to examination table
- Possibly take some clothes off
- Listen to directions

- Listen to what the doctor thinks it might be
- Doctor explains treatment plan
- Doctor might refer to specialist
- Informs about prescription

START TREATMENT

- Get in line
- Wait for them to find medication
- Pay

- Take medication out of packaging
- Skim medication instructions
- Take pill at the right time
- Set reminder
- Put in pill case

FOLLOW UP

- Tell story and symptoms again
- Physical examination

- How much do I explain?
- Do they know/look at my health history?

- Am I going to embarrass myself?
- Am I doing it right?
- Am I normal?

- Should I buy the cheaper alternative or the branded one?

- Is it going to be different this time?
- What has changed since last time?
In order to evaluate which opportunities were the most interesting to focus on, they were mapped on top of the current customer journey. This revealed that the 3 on the top row (quick access medical records, universal two way provider sharing and sectioned medical records) were predominantly beneficial to healthcare practitioners and were removed. The most interesting opportunities were the ones not present in the existing customer journey, on either edge such as the annual home test and preventative follow up plan. Additionally, I wasn’t interested in working within the current healthcare experience framework, as it seems constrained by today’s pain points. Considering the rise of digital health platforms there is a lot of potential of embracing digital platforms and disrupting today’s health service offerings.

**Analysis**

**Opportunity Mapping**

Early in the synthesis process I developed 6 sacrificial concepts that I presented to oncologist Beatrice Melin and molecular biologist/product manager Arianna Gianola to help me gauge reaction, to determine which opportunity areas were probably the most interesting. One unexpected learning was the importance of patient empowerment in a larger scale than I had originally visualized. Beatrice informed about the legal limitations of including family members in digital records and how it is really important to have some sort of a genetic counselor or a coach that understands the implications of genomic data. Beatrice also explained how difficult it is to follow up with young adults who’ve had childhood cancer and who’ve now moved to a different part of the country. Having a health check-up kit that can be mailed to them, or the ability to text with them as a way of following up would be very useful, especially for the younger generation.
1. Health Coach & Genetic Counselor

A healthcare system that incorporates genomic and quantified data would require the use of experts to interpret data and deliver meaningful insights to the user. A genetic counselor would be trained in interpreting DNA results and presenting the information in a way that is actionable and understandable to the user. Similarly, a health coach would give feedback and guidance on the quantified self data and would be knowledgeable in behavior change and triggering positive health actions. A combination of these two types of health advisors would be a powerful team.

2. Health Goals & Action Steps

Because today’s health system is primarily focused on sickcare rather than healthcare, there is no systematic guidance on preventive health and how to set health goals and action steps that are achievable. Highly motivated people might do this individually, but it is not a part of the health system. One of the responsibilities of the health coach is to help set action steps related to each person’s genetic results and quantified self information.

3. Follow-up & Counseling

Follow-up and counseling are important in order for healthcare to be more than a sporadic visit to the doctor with diffuse communication about previous experiences with medications. To foster mutual trust and understanding, there must be regular encounters of interaction and communication. Follow-up and counseling are important for creating long-term health awareness. Being able to ask questions and to get feedback from a health coach are important for this behavior to be experienced as something positive. It is also important that there is a short-term and a longer-term health plan personalized for every individual.
5. Patient Participation
Medical records are often partially inaccurate and incomplete. Normally, patients are denied access to their own records, and if they do have access it is merely in paper print out format. Today’s medical records primarily exist because of legality and for practitioners to look back on. If medical records were designed in such a way that patients could have access and participate in writing notes or adding information, it would not only keep the patient more informed about their health, but would be great for correcting mistakes and misinterpretations.

4. Family History in Medical Records
Many people do not have access to their family medical records, and/or are not aware of what medical conditions have impacted their family history. Until now, family history has been the most important tool in determining risk factors for hereditary disease. Combining family history with genomic information will result in even more powerful tools for finding areas of health risks. Being able to link family members’ medical records could help healthcare practitioners identify patterns in the family history and could help a counselor more quickly identify genetic risks.

6. Home Testing
Since there are already a lot of different kinds of at-home testing kits on the market, this concept explored the option of choosing between many different at-home testing kits, such as HIV, yearly health kit, STD testing, etc. The thought was that people would be able to pick out kits appropriate to the information they wanted, so that different levels and ranges of testing could be provided. Some may want comprehensive information about their entire genome, while others may just want to check for the BRCA genes, or current cholesterol levels. Separate tests for STD’s, or gluten and lactose intolerance could be added on to the purchase of a genetic test.
SERVICE PRINCIPLES

Based on the opportunities I found common elements relevant to user needs throughout the service experience. These 4 principles are below.

LOW PARTICIPATION THRESHOLD

Make it easy for me to engage

PATIENT EMPOWERMENT

Support me in making health decisions.

COMMON LANGUAGE

Speak to me in a language I understand.

DIGESTED CONTENT

Show me what’s relevant to my health.

ELIMINATING THE DOCTOR’S OFFICE

Considering that so many of the pain points of today’s healthcare experience involves going to the doctor, why not just eliminate the doctor’s office entirely? Going to the doctor requires planning ahead, a scheduled appointment and there is also an expectation that the patient is sick in some way. What if healthcare instead was on demand when people need it. What if people didn’t have to be sick to go to the doctor for a health checkup?
Today’s health journey is primarily an irregular series of one time appointments, a quick fix that usually lacks follow-up or a preventive focus. Considering the need for a more circular journey, IDEO has developed a framework called the adherence loop. It is particularly used for creating an adherence to a service or system, or to foster behavioral change. Using this adherence loop framework is especially important when considering a preventive healthcare service, where people are active participants in managing and maintaining their health.

**Maintenance care**  
occasional interactions with doctor at clinic

**Acute care**  
one time interactions with ER at hospital

**Preventive care**  
continuous interactions with health coach online

**Adherence loop framework**
I created 5 personas that would help me ideate around their needs. The personas were a first attempt at exploring different stories related to how or when genomics and quantified self data could be integrated and useful. An example story was Leola’s below. The other personas can be found on page 60-61 in the appendices.

**Leola**

Leola has just given birth to her second child at age 35. As she has been aware of a strong family history of breast cancer since she was 15 years old and her grandmother died, she has taken a genetic test only related to breast cancer genes, and found that she has the BRCA 1 gene. Because of this, she is on an extremely close follow up plan, in order to detect cancer sooner than later and she is considering having a double mastectomy. She feels a bit unsure about what to do and is going through genetic counseling and preventive health guidance to help make the appropriate decisions.
As a part of the ideation process tokens were created to represent different aspects of the healthcare journey. These tokens included locations such as home, hospital, doctor’s office. People were different kinds of doctors, coaches and genetic counselor. Data included quantified self data, genomic data and different data input such as activity tracker, iphone application and blood test. Additionally there were also different emotion tokens and tokens for different touchpoints. By using these tokens as a way of constructing the journey of the persona, it was easier to ideate what does not already exist in today’s health journey. By repeating this process with the different personas that all had different health concerns, I started seeing a lot of similarities. The ideas that kept repeating and could be applied to more than one person were a health coach or genetic counselor, feedback and follow up on progress, using an application for tracking, digital communication, creating long term health plan and having actionable steps. An example of Leola’s journey is below.

Since this is a service design project, it is natural that there would be several touchpoints, so the different ideas would likely be combinable into a holistic experience. By noticing that many of the journeys had similar ideas around planning ahead, having an input device and doing a genetic test that informed them of what actions they should take, I decided to host a workshop to see how people who had not done a genetic test before would react to it, and how they might want to experience it.
The ideation workshop I hosted involved 8 peers. The workshop had three parts. It began with a pre-workshop task to draw a healthmap that was handed out to 20 peers. The healthmaps helped visualize how people view their health. Some people drew the things that help them stay healthy and some people drew the things that contribute to them not feeling healthy, but most drew a combination of both. See Appendix X for photos of all the healthmaps.

The second part of the workshop was a simulation of the DNA testing experience. I had half the people do a cotton swab saliva test as patients while the other half were doctors and had to deliver the genetic health risks. The reason for doing this was not only to get people into the headspace of the project, but also to have an experience to react on, in order to come up with ideas for the third and last part.

The third part was a brainstorm with six ‘how might we’ questions. The statements and questions were:

In the future you will have a data doctor. What qualities might he/she have? What information might he/she communicate to you?

In the future you will manage your health from home. What tools might help you participate in your own health management?

In the future you will have a dna test done. What might the genetic testing experience be like? How might the results be communicated to you?

In the future you will have a chip inside your body. How might the chip data help you stay healthy?
Workshop Outcome
One understanding that emerged was of the desired qualities of the health coach (data doctor) such as: always being available, friendly, and more like a personal trainer.

The discussion emphasized the importance of the results paving a path forward with step by step guidance. Presenting the results must be done in a sensitive way, including both positive and negative health risks, with an emphasis on what can be done, and an avoidance of numbers. The “chip in the body” raised a lot of gamification of health ideas, such as a reward system if you stop smoking, or if you live a healthy lifestyle and reach your goals you can have the chip removed.

At home health management brought up many ideas around a smart internet of health objects, such as connected toilets, toothbrushes, beds, and the ability to be your own doctor based on the information these objects communicate.

BLUEPRINTING THE EXPERIENCE
In service design it is easy to add ideas to the service creating a ‘unicorn’ service which does too many things, while it is much harder to achieve the right balance of a service that does one thing well. Through blueprinting the experience, using the adherence loop as a framework, the experience began to take place as a service, rather than many random ideas put together. The blueprint represents the skeleton and structure of how the different interactions are connected.
The OME Precision Medicine Summit hosted by UCSF in May 2013 gathered 170 of the world’s leaders in Precision Medicine. Many of the concepts shown were inspiring, including a ‘precision medicine health care grocery store’.

Prevent (www.preventnow) is an inspiring service because they took something very specific, like diabetes, and created a course structure and coaching to help people who have pre-diabetes but with the aim of preventing it from emerging.

Pill Pack (pillpack.com) is another inspiring service. It communicates very clearly to the consumer how the system works. Although it is a pharmaceutical product, it feels very down to earth and relatable.
CONCEPT

OVERVIEW OF CONCEPT

From a combination of analysis, ideation, blueotyping the service, looking at existing health services, sacrificial concepts and design principles, I decided to focus on a preventative health plan concept with at home participatory health, action steps, and health coaching and follow up.

Kolla Hälsa is a preventive healthcare plan which provides proactive health guidance initially focusing on people between 20 and 40 years of age who do not currently interact with the healthcare system. A healthcare kit is mailed to the user’s home, where a saliva sample is taken that is mailed back to a lab for analysis. The analysis includes a genetic profile of health conditions the user might be predisposed to. Two weeks later these results are communicated through a video call with a health coach. The health coach helps the user create achievable short term actionable steps and a longer term health plan, with a primary focus on preventive actions. A mobile application provides subtle prompts and cues trigger actions, while the health coach provides feedback to reinforce positive behaviours.

MAIN PARTS OF SERVICE

Website: The website has a video promoting the service, a section explaining how it works, stories from participants and the ability to sign up and order the kit.

The Kit: A kit is mailed to the home, with instructions on how to give a saliva sample, that is mailed back to laboratory.

Website Logged in: The logged in portal of the website provides access to video-calling a health coach, viewing health predictions and actions.

Mobile Application: The app provides on the go reminders and tracks actions and progress over time.
CONTEXT WITHIN HEALTH SYSTEM

Kolla Hälsa is a healthcare initiative by Västerbotten Läns Landsting and has 1177.se as a collaboration partner. Like all other public health care services, it is predominantly funded by the Swedish government, but participants pay a small percentage (symbolic fee).

CUSTOMER JOURNEY

The customer journey is structured in accordance of the Adherence Loop developed by IDEO. The purpose of the journey is to create a loop of consistent interactions rather than a linear one-time engagement and to explain the scenario of events which follow each other.

1. BELIEVE
Believe that preventative health is a way to be more aware of and participatory in health decisions.
1a. Learn about service on Website
1b. Order kit on Website
2. FRAME
Get started by receiving the starter kit and giving saliva sample.
2a. Respond to additional questions
2b. Kit arrives in mail
2c. Read instructions
2d. Give saliva sample
2e. Place tube in envelope and mail back

3. KNOW
Learn about health predictions and preventive actions with Health coach.
3a. Receive email that results are ready
3b. Log in to Kolla Hälsa
3c. Start video call with health coach
3d. In conversation with coach hear results
3e. Decide which action steps are doable for you
3f. Edit action step to what works for you

4. PROMPT
Subtle cues and prompts are sent to trigger action.
4a. Receive push notification to encourage action
4b. Receive push notification to fill in actions that have been done at the end of the day.

5. ACT
Actions are tracked and visualized providing an overview of health.
5a. Do action
5b. Actively track daily activity
5c. See progress

6. REINFORCE
Health coach follows up and helps adjust actions based on progress.
6a. Follow-up with health coach
6b. Adjust actions

USER STORIES

Evelyn’s Story
It wasn’t until my aunt was diagnosed with breast cancer that I started thinking about my own health. I always assumed I was healthy and that I shouldn’t worry until I was much older. My cousin told me about Kolla Hälsa. She told me it was a preventive healthcare plan to help you take care of your health, especially while still young. I haven’t been to a doctor in years, and I avoid going as it always seems like a quick fix rather than looking at my overall wellbeing and health. At first I was worried about what the results would be. Would I have the breast cancer gene? My health coach, Keegan, reassured me. He told me that I had a higher likelihood of getting breast cancer, but that there are things we could do to prevent it. I also discovered that I have a higher likelihood of age-related macular degeneration and we talked about how I feel stressed at school and how to cope with it. Together we created a list of actions I could do to take better care of my health. It was important to me that the actions felt like things I wanted to do and that they weren’t prescribed. Since then, I’ve started cooking more from scratch, I always walk up the stairs, and I really feel like I’m in control of my own health and that I know what I can do to avoid breast cancer.
Hugo’s Story
I grew up in Järpen [in the west of central Sweden]. My mom is a bit old fashioned and still wanted to have cows on the farm, even though it does not make sense financially. So we have five cows, and she would make her own cheese. Not drinking a glass of milk everyday wasn’t an option. I’d always had stomach problems, but I thought it was because of drinking too much cola, that’s at least what my mom told me. So I decided the stomach pains weren’t a big enough deal and stopped worrying about it.

In my biology class we were discussing hereditary health conditions and not knowing my father, I got curious about how I could find out what health conditions I might have inherited from him. Later in my class we talked about Kolla Hälsa and gene tests, so I ordered the kit.

It turns out I’m allergic to milk, and I’ll likely get a double chin and become overweight unless I start doing some physical activity, and drinking less cola. My health coach also asked me if I smoke, and we had a good long chat about how that increases my likelihood of lung cancer. We talked about a plan for smoking less and maybe even one day quitting. I’m not someone who ever goes to the gym or to the doctor, so at first it was a bit weird to answer such personal questions, but it was a good eye opener and at the end of the day I feel like I probably need to start now with some healthier habits. There’s no way I can quit drinking cola, but I figure I don’t need to drink half a litre of it every day.
**KEY PARTNERS**
- Socialstyrelsen
- Vasterbottens Lans Landsting
- 1177
- Umeå University Hospital Laboratory
- Arbetsförmedlingen

**KEY ACTIVITIES**
- Preventative health kits of genetic analysis
- Health action and tracking software

**VALUE PROPOSITION**
- Preventative health focus - know now, so you can prevent in the long run.
- Patient empowerment - you’re in charge of your health.
- Your health coach has time for you and cares about your overall health, not sickness. Here to support you in making health decisions.
- Action steps and health goals give you bite size pieces that are easy to act on.

**KEY RESOURCES**
- Genetic counselors and health coaches
- Genetics analytics software and laboratories

**COST STRUCTURE**
- **Staff** - IT, Health coaches, Genetic counselors and Laboratory staff.
- **Software** - Analytics software and consumer facing applications
- **Laboratories** - DNA sequencing and analytics
- **Kits** - Postage, packaging, marketing materials
- **Incentives** - potential financial incentives for living healthy, could be supported by employer or Arbetsförmedlingen
**CUSTOMER SEGMENTS**

Primary - 20-40 year olds who have no or very little contact with the health system. They always google their symptoms before deciding if they have to go to the clinic or not.

Secondary - 17-20 years olds who are in the transition period from home to developing their own health habits.

Secondary - People who have acknowledged that they want to make a change in their health due to family history discoveries, weight loss, etc. Would be subscribed by their doctor to use this service.

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**CUSTOMER RELATIONSHIPS**

Website information  
Emails  
Online video chat  
App notification prompts

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**CHANNELS**

School nurses and educational institutions  
1177.se  
Localvården (local clinics)  
Pharmacies

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**REVENUE STREAMS**

Subscription fee - 500 SEK  
Kit Sales - 500 SEK  
Funding from Government - Substantial
DESIGN RESULT

The design areas that I’ve focused on are the website where users can learn about the service, the physical kit, the experience of hearing the results with the health coach and the application for tracking actions. This section will walk through the aspects of the design in more detail, explaining it’s behaviour.

1. BELIEVE

Believe that preventative health is a way to be more aware of and participatory in health decisions.

1a. Learn about Kolla Hälsa on Website

www.kollahalsa.com

The video (vimeo.com/96824743) is shown in the slideshow on homepage of the website and is a commercial for the service. The intent of the video is to give a glimpse into the service and encourage people to order their preventive health kit. The mood of the video is upbeat and encouraging.
DISCOVER WHAT PREVENTATIVE HEALTH ACTIONS YOU CAN TAKE.

Most chronic conditions such as obesity, breast cancer, diabetes, lung cancer can be prevented if discovered early in life and acted upon.

DISCOVER YOUR HEALTH PREDICTIONS
Unlock the secrets of your DNA and get to know your health from the inside out.

ENGAGE WITH YOUR HEALTH COACH
Your health coach is like a personal trainer for your health, supporting you along the preventive healthcare journey.

CREATE YOUR ACTION PLAN
Together with your health coach, you create actions to integrate into your daily routines, developing a long-term health and wellness strategy.
How it works explains process steps in a photo sequence. Unlike many of the other genetic testing companies that use line drawing illustrations, Kolla Hälsa uses photographs of real people using the different aspects of the service, such as the spit tube, the packaging, the health coach and users using the application. This is done so that the service feels more human, and not as clinical.
Stories of participants are written from a first person point of view, so that they feel genuine, rather than Kolla Hälsa’s marketing team spinning the stories in the company’s favour. Prospective users want to hear the stories of others who have been through the service, without a marketing filter. Users submit their own stories.

1b. Order kit on Website
Ordering the kit is done online, and requires the user to fill in their Swedish personal number, so that the information can be digitally linked with their existing health profile “mina värdkontakter”. The user pays 500SEK for the kit, which is a small percentage of the actual cost, similarly to what it is like going to the doctor in Sweden.
2a. Respond to followup questions
In the order confirmation email there is also a followup survey. The questions are primarily targeted towards family history and current health concerns or aspects of health they are interested in learning more about. This information helps the health coach and genetic counselor better provide personalized and useful information to the user.
2b. Kit arrives in mail
The kit usually arrives within 2-3 business days. The shipping packaging is discreet in a plastic mailing envelope in which the box is placed inside. On the outside of the kit, there is a handwritten “Hej” (Hi in Swedish) followed by the user’s name, so that the user knows the kit is pre-registered in that name. The kit consists of two parts, a tube for saliva, and an envelope for placing the tube inside and mailing it back to the laboratory.

2c. Read instructions
The instructions are printed directly on the box and consists of illustrations because it is easier and quicker to decipher the meaning of illustrations.
2d. Give saliva sample
The second step of the instructions is to remove the cap, and to spit in the tube. It takes most people between 2-5 minutes until they have filled the tube with saliva. Once the tube is filled, the cap is replaced.

2e. Place tube in envelope and mail back
The third and last step is to place the tube in the envelope and mail it back to the laboratory. The envelope is pre-paid and already has a plastic lining within the envelope so there is no need to place the tube into a specimen bag and then into the envelope.
3. KNOW

Learn about health predictions and preventive actions with Health coach.

3a. Receive email that results are ready
The email uses language such as “we are ready when you are”, emphasizing that the patient is in control of when they’d like to hear their results.
3b. Log in to Kolla Hälsa
The logged in portal of Kolla Halsa is similar in design to the promotional website, but has very different content. Here the content is very focused on actions within the service. When logging in the first time the large image highlights that the first action is to start the video chat with the health coach. The other information such as predictions and actions is not available until the first chat with the health coach.

3c. Start video call with health coach
Starting the video call with the health coach is as easy as clicking a button and a video call will start within the same window in the browser.
3d. In conversation with coach hear results
The conversation with the health coach starts out very casual with the coach getting to know the user. The coach asks questions related to their lifestyle, where they work, go to school, if they do any sports or have any allergies. This information is really important for the coach to be able to alter the actions so that they feel personalized and fit the individuals lifestyle. The coach then proceeds to introduce one block at a time of a likelihood with the corresponding suggested actions. Only about 2 - 4 of these blocks are presented, based on the individual genomic results. Likelihoods that do not have any preventive actions are not shown, and there are never any numbers shown, just a statement of increased or decreased likelihood. The word likelihood was chosen instead of the word risk, which is used by most genetic testing companies. Likelihood is meant to sound less scary and less like a finite result.

![Webpage screenshot showing preventive actions table]

- Earlier scheduled mammography
- At home breast exams
- Full BRCA gene testing

**Reduce the likelihood of breast cancer**
- Yearly eye exams
- Eat a salad
- Snack on nuts
- Eat fish for dinner

**Reduce the likelihood of age-related macular degeneration**
3e. Select actions
The action steps are presented as the focus of the conversation, taking away the emphasis of the results. The health coach initiates a conversation of what seems doable for the user compared to their current habits and what they have a desire to do. It’s important that the user feels in control of making the decision and that the action feels within reach. For instance if a suggestion is to eat fish once a week, but the user does not like fish, then the coach can suggest an alternative. Some of these actions will be long term and some will be short term and actionable right away. The emphasis of the service is that each user has their own individual plan that they believe in following through with.

3f. Edit actions
The action steps are edited by the user and not the health coach in order to ensure it is the users own decision and that they feel like an active participant in the process.

<table>
<thead>
<tr>
<th>Earlier scheduled mammography</th>
<th>age 27</th>
</tr>
</thead>
<tbody>
<tr>
<td>At home breast exams</td>
<td>2 / month</td>
</tr>
<tr>
<td>Full BRCA gene testing</td>
<td>order test</td>
</tr>
</tbody>
</table>

Reduce the likelihood of breast cancer

<table>
<thead>
<tr>
<th>Yearly eye exams</th>
<th>schedule</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eat a salad</td>
<td>2 / week</td>
</tr>
<tr>
<td>Snack on nuts</td>
<td>4 / week</td>
</tr>
<tr>
<td>Eat fish for dinner</td>
<td>1 / week</td>
</tr>
</tbody>
</table>

Reduce the likelihood of age-related macular degeneration
4. PROMPT

Subtle cues and prompts are sent to trigger action.

4a. Receive push notification to encourage action
The notifications range from recipes, a suggestion that it is a nice day for a walk, a reminder to do a breast exam.
4b. Receive push notification to fill in actions
At the end of the day, right before bedtime (the app learns when you go to sleep) you get a reminder to fill in which actions you’ve done. The frequency of the notification depends on the frequency on the actions listed.
5. Do action
The application has the ability to passively track activities if connected with an activity tracker or any other applications on the phone, such as sleep cycle, human, moves, etc. The Kolla Hälsa application becomes the central point for all health data and uses the other applications for their established algorithms. This also allows the health coach to inform the user to install certain applications in order for them to be linked.
5b. Actively Track daily activity
Upon opening the app only the top 4-5 actions will be listed. They are ranked based on how frequently the user is supposed to do the action and based on how long it has been since the last time they did the action.

5c. See progress
The progress can be seen in the health overview both on the phone application and in the website portal. This information displays how the user is doing at achieving their actions.
6a. Follow-up with health coach
The health coach can also see the progress of the user and will send a message through the application to ask how things are going if he can sense that a user is consistently not engaging in a particular action.

6b. Adjust actions
Through this conversation they come up with a better action that meets the same goal. Some users might be exceeding their goals and then the health coach can help them create new goals based on their needs and desires. Throughout this process the health coach acts merely as a supporter, much like a personal trainer, but has the knowledge to back up his reasons for why an action might be good for the user to participate in. Adjusting the actions is done similarly to editing actions, and it is the user that does the actual changes.
Some interesting stories and thoughts were revealed from discussions around the concept both before, during and after the exhibition. Feedback appears to differ depending on the culture of the person making the comments. Those from North America are, in general, exposed to the concept of an annual checkup. Several people have brought up that in Scandinavia and the Netherlands, in order to get a full checkup, one needs to fake symptoms. Additionally, native Scandinavians have also stated that it would be great to be able to talk to a doctor without needing to be sick, but to see how their health is.

When asked about their views on preventive health, people often mention how they take preventive cautions by going to the dentist every year. There seems to be two reasons for this, primarily because they have to cover their own costs for dental repair, and therefore have a financial incentive for visiting the dentist more frequently. Secondly, people have been trained at a young age that one should go to the dentist every year. This indicates that more consideration should be focused on the business model, as it will likely impact the way people both interact with their health and how they engage with a service like Kolla Hälsa.

Other feedback has been regarding how much information they would like to share with their health coach. Here people are quite split in terms of willingness to share information and privacy concerns. Some people have also raised questions about what if the genetic information is bad, or what if they get discriminated against because of their genes. This highlights the need to be very clear about what happens to this data, who owns it, who can access the information, and what might be the longer term consequences of knowing genetic information.

Another concern brought up by people specifically in the interaction design field is, How long can people actually be engaged by this service? Especially when considering the action steps and retention rate, how long would it take before people turn off the push notifications or they stop doing the actions, if they even start at all? These are some very valid concerns, and it might be a good idea to develop the action steps in collaboration with a behavioral psychologist. It is also very important to beta test the application to see how people actually react to the application behaviours of push notifications and actions.
Unlike my initial thoughts, this project became very now-driven. Healthcare is one of the areas of design where there are a lot of immediate opportunities to focus on, and I dived into a concept that people can hopefully relate to through a preventive healthcare package. I view Kolla Hälsa as only a starting point of harnessing the importance of genomics for the future of healthcare, so I want to expand a bit about how I foresee this concept being extended in the future.

Two main components which I think will be increasingly interesting to explore is social aggregation and integrated smart devices. Social aggregation and suggested actions based on your family, coworkers or classmates health and location would allow more predictive and personal actions. For instance, stay home today, or else you’ll get your peers sick. One way of gathering the health data needed would be through connected devices in the home such as the smart toilet, toothbrush etc and give daily updates on health status. These devices would provide digested information, not data. For instance, you need a bit more fiber in your diet, try adding musli to your yoghurt for breakfast.

Implementing a concept like Kolla Hälsa in Scandinavia would first of all require buy in from healthcare practitioners and would need to be supported by the county administrations. Considering that is quite a substantial effort, it would probably need to be released as a trial by one of the medical universities in order to gain public trust. But even before that there are a number of obstacles. Some healthcare practitioners might disagree with the use of, firstly genomics data for the general public, and secondly, the strong focus on preventive healthcare. Although the costs of preventive healthcare can outweigh the potential costs later in life, many people might disagree and feel that there are too few resources to both treat sick people in an efficient and timely manner, as well as spend money on preventive healthcare.

Another obstacle is that the training of doctors, health coaches and health care practitioners needs to include more knowledge about genomics and behavioural sciences. These changes to the education will likely take several years to pass at the university level and it will be about a decade or so before these healthcare professionals will join the workforce.

Considering the public discussion in Sweden caused by people having access to their own medical journals, people will likely have strong opinions for or against a service such as Kolla Hälsa being a good use of the government’s healthcare budget. Kolla Hälsa might be received differently if it were offered through healthcare insurance, rather than the public healthcare system. The reasons for these concerns are usually related to ethics, privacy, and the security of the personal health data. It is important to consider how much data and what kind of health data is shared. Building out a connected, integrated and predictive digital platform for healthcare would also require substantial costs and maintenance. It would be best carried out as an integrated part of the public healthcare system, which is not yet fully connected between hospitals, doctors’ clinics and patients.
Initially I thought I would be working on a project focused on a future vision of healthcare. In the end it turned out to be a very down to earth result. I think this is because of the strong focus on user-centered design. Healthcare has many immediate needs and design opportunities and it was easy to get caught up in what is doable today. Additionally, when seeking feedback from practitioners they are very focused on the possibilities of today and do not think particularly far ahead, so when collaborating with them, it is even easier for the concept and the design to be grounded in what is realistic and needed today.

A lot of the reflection in action has been on my own personal development as a designer and realizing what I’m good at and what I’m not as good at. I’ve realized I enjoy the actual researching and designing more than I do project management and coordination. The aspect of the process I’ve enjoyed the most is hearing peoples stories and synthesizing the information into design opportunities, and then developing the concept into a service and its multiple touchpoints.

I’ve also found working solo can be limiting at times and I find it coincides with feeling blinded by my own thoughts, without the rich discussions and ideas that arise through teamwork.

If I were to do this project over again, I would probably start with a much narrower scope, and tie it to a stakeholder or collaborator with a clear need. Considering I started with a very broad topic of precision medicine and opened it even wider during research to include healthcare in general, the scope of the project was a lot to digest. I think I thoroughly enjoyed how open the project was, but it also limited me in how deep I was able to dive into the topic. If my scope was more narrow, it would’ve been easier to dive into the details of the experience much earlier and the end result would hopefully feel more finalized.

This project also emphasized the importance of iteration. Near the end, I only had time to do a few iterations of the website, the application and the packaging, and for every revision it got better. But these iterations take time, it takes time before it dawns on me that it isn’t really working and it also takes feedback from people to realize what is not working. I think in the future I would like to get more people’s opinions sooner in the process, to helpfully move through the iteration phase quicker.
I would like to send a big thanks to my peers, my class, everyone I’ve interviewed, everyone who took the time to reply to my emails, my dad, the professional helicopter and proof reader, and especially a big thank you to my tutors Jennifer and Tara for guiding me along the journey.

Jennifer Sarich-Harvey  
*External advisor*

**IDEO**

Arianna Gianola  
*Industry advisor*

**INVITAE**

Tara Mullaney  
*Project Tutor*

Jennifer works as a Senior Interaction Designer at IDEO Boston where she has been involved in many healthcare projects. She also did her masters thesis on a related topic called “project genetica”. Through biweekly skype meetings she has played a very active role in the project in terms of both guidance and inspiration.

Arianna works as a Project Manager for User Experience at Invitae, a clinical genetic testing company in San Francisco. Invitae primarily focuses on genetic testing for cancer and patients have to be referred by their physician in order to do testing. Arianna has been very helpful in providing knowledge of the current challenges facing the rise of precision medicine and insight into how genetic testing is currently being done.

Tara is a PhD Student at Umeå Institute of Design, and is a scientist-turned-designer that loves exploring the realm of emotions and experiences. Her dissertation is *Thinking Beyond the Cure: Experience Design and Healthcare* working very closely with the Radiology department at Norrland University. Tara has played an important role in helping me navigate the project and asking the big questions along the way, while still keeping my feet grounded.
REFERENCES


Bipartisan Policy Center (August 2013) “F” as in Fat: How obesity threatens America’s future (TFAH/RWJF)


APPENDICES

APPENDIX B – PERSONAS

PHILIP

Chronically ill
Mental & physical
Depression
Back pain & Arthritis
Undiagnosed health issues
8 Medications

Philip is in his 50s, has multiple health conditions, both physical and mental, that he is trying to cope with. He has a doctor’s appointment every three months, but has found that no new action has started to come out of it. He also feels that he probably has some health conditions that have never been diagnosed, but his doctor already thinks he is a hypochondriac, and he feels bad about going to the doctor so frequently and always complaining about his pain. He also feels that because he has manic depression that his doctor often doesn’t take him seriously as he thinks it’s just a symptom of his other medications. Philip has about 8 different medications that he needs to manage several times a day. He finds it mentally draining not knowing what is wrong with him and wants to dig deeper in what might be the cause.

EVELYN

Rarely ill
PAP test
Anti Medication
Self-diagnoser
Avoids medical system

Evelyn is in her late 20s, and avoids going to the doctor as she feels it consuming and she isn’t really interested in taking medication to solve the problem. The only times she goes is to go in for her regular PAP test, if she has a yeast infection and knows she needs antibiotics in order for it to go away. She also always googles the symptoms and what she thinks her diagnosis is, in order to see what the treatments options are. She is usually always right. The rest of the time she is healthy and there’s no need to interact with any part of the health system.
LISA

Rare genetic condition
Stages of Genetic discovery
Tracking behaviour
Contributing to research

Lisa has just started university and is 21 years old and has an extremely rare genetic condition called ______ which was discovered through genetic screening at birth. This means she has a very strict diet she needs to keep in order to stay in balance. Her disease also affects other aspects of her health, but since it is such a rare condition scientists don’t know very much yet. Her doctor has created an application that helps track her food intake, her location and different body data to see what the triggers might be and if there are patterns in her seemingly random symptoms. When she turned 20 years old she decided to unlock the rest of her genetic information, to see what other genetic conditions might affect her one day, and to then be prepared.

LEOLA

Breast cancer
Brca gene
Genetic counseling

Leola has just given birth to her second child at age 35. She has been aware of that there is a strong family history of breast cancer since she was 15 years old when her grandmother died. She has taken a genetic test only related to breast cancer genes, and was found that she has the BRCA 1 gene. Because of this, she is on an extremely close follow up plan, in order to detect cancer sooner than later and she is considering having a double mastectomy. She feels a bit unsure about what to do and is going through genetic counseling and preventive health guidance to help make the appropriate decisions.

SILVIA

Diabetes risk
Preventive health
Action steps
Data doctor

Silvia is 48 years old and has discovered through her genetic test that she has a higher likelihood of getting diabetes type 2. She really scared her, and she approached her doctor of what to do to avoid getting diabetes. Silvia was sent to a special doctor who focuses on preventative health. There she was given a special program with actionable steps based on her lifestyle, ability and health.
## APPENDIX E - SACRIFICAL CONCEPTS

### LISA'S HEALTH GOALS

<table>
<thead>
<tr>
<th>HEALTH RISK</th>
<th>GOAL</th>
<th>ACTION STEPS</th>
</tr>
</thead>
</table>
| Age-related macular degeneration           | Eat more leafy green vegetables, bright colored vegetables, fish and nuts. | - Eat fish once a week.  
- Eat a salad 3 times a week.  
- Bring nuts to work to snack on |
| Slow Metabolism                            | Reduce caffeine intake              | Step 1: Only drink 2 cups of coffee/day.  
Step 2: Only drink coffee for breakfast. |
| Stress                                     | Sleep more                          | Step 1: Track sleep with Sleepcycle.  
Step 2: Turn off phone at midnight.  
Step 3: Increase sleep by 30 min. |

### FOLLOW UP WITH LISA

**How are you feeling?**

**Feeling dizzy still... I'm taking half the medication dose.**

**How is the medication working?**

**Better than the previous, I'm not as nauseous s before.**

### LISA'S FOLLOW UP PLAN

<table>
<thead>
<tr>
<th>HEALTH ISSUE</th>
<th>FOLLOW UP</th>
<th>FREQUENCY</th>
</tr>
</thead>
<tbody>
<tr>
<td>cancer remission</td>
<td>blood test</td>
<td>monthly</td>
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<tr>
<td></td>
<td>CT scan</td>
<td>6 months</td>
</tr>
<tr>
<td></td>
<td>endoscopy</td>
<td>6 months</td>
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<td></td>
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<tr>
<td>mammogram</td>
<td>mammogram</td>
<td>yearly</td>
</tr>
<tr>
<td>age-related macular degeneration</td>
<td>eye-checkup</td>
<td>yearly</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12/03</td>
</tr>
</tbody>
</table>
FAMILY HISTORY IN MEDICAL RECORDS

FATHER'S MEDICAL RECORD
HEREDITARY

MOTHER'S MEDICAL RECORD
HEREDITARY

MAY HAVE INHERITED
LISA'S MEDICAL RECORD
HEREDITARY
GENETIC CARRIER

CHILDREN'S MEDICAL RECORD

PATIENT PARTICIPATION

LISA'S MEDICAL RECORD

March 7, 2014
Lisa came in for her annual check-up for mammogram after having reported a lump in her left breast.

Lisa
Right breast. Have also been feeling very tired lately.

November 30, 2012

HOME TESTING

- Home testing Diabetes
- Home testing Pregnancy
- Home testing STD's
- Home testing HIV
- Home testing ERICA
- Home testing Blood Test
- Home testing Gluten
- Home testing Lactose
- Home testing Parkinson's
- Home testing Alzheimer's
- Home testing Warfarin
- Home testing Obesity
APPENDIX G - BLUEPRINT 1/2

Pick up kit at pharmacy

Learn about service on website

Sign up & order kit

Receive kit in the mail

At checkout kit is registered with person number (healthcard)

Survey response linked to profile for analysis and action steps

Kit is activated

Pharmacist explains benefits

Touchpoint/User Action

Health Coach

Back Stage Staff

System

Adherence Loop

Believe

Frame

Physical Evidence

Kolla pharmacy/kit
Open kit and read instructions

Provide saliva sample

Return kit in mail

Receive notification that results are ready

Login to personal health web portal

Staff takes into consideration survey responses and selects "increased" & "decreased risk"

Laboratory links kit with persona number, and survey response.

Results linked to personal page to be unlocked by healthcoach

Name of available health coach appears
APPENDIX G - BLUEPRINT 2/2

Learn health results, step by step.

- Starts with an overview, then the most serious to positive characteristics.

Set action steps and longer term health plan

- Asks which actions they feel are achievable

Edit actions

- Co-edits. Asks what is a reasonable timing

Learn about tools to use to help achieve goals

- Explains health tools available

Receive notification reminding of actions

- Feel like they come from your health coach.

Results unlocked by health coach as conversation progresses

- Appointment requests are sent off to appropriate doctor

Actions automatically sent to appropriate category, daily, weekly, monthly, long term.

Sends notifications based on actions and tracking habits.
ACT

Do action (passive tracking)

System uses the passive data to learn about behaviour to trigger timely push notifications

REINFORCE

Input completed action items at end of day. (active tracking)

System sends a daily push notification to fill in actions.

See own progress over time

Passive & active data is collected, synthesized and presented as an overview.

Receive feedback on progress from health coach

Notes added in system

Adjust actions/goals with coach input

Healthcoach looked at progress and gives pointers on what is going well and what could be improved.

Posts a suggested goal

System is updated