HEALTH DATA FROM AN INDIVIDUAL AND SELF-CARE PERSPECTIVE

By Hanna Svensson

Innehåll

This report was produced as part of Swelife's precision health project Sweper. Sweper is a national initiative that has the objective of improving and supporting opportunities for the life science sector in Sweden to obtain and use data.

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HEALTH DATA FROM AN INDIVIDUAL AND SELF-CARE PERSPECTIVE

Summary

This report aims to increase the dialogue concerning health data and to shed light on self-collected health data from the perspective of the individual. It describes what self-collected health data is, and how it can structure it. The focus is on individuals with long-term or chronic medical conditions.

Health data is information that concerns the health of an individual, or a group as a whole. This may be anything from weather data to measurements and self-assessments taken by the individual. In the context of self-collected health data, data is measurements or assessments of different symptoms and conditions. Examples of measurements can be blood pressure or body temperature, and examples of an self-assessment can be how tired or stiff one feels they are.

A selection of academic articles has been studied, consisting of articles both on self-care and professional health and medical care. The articles on self-care describe the importance of measuring and logging what is important for the individual and that this is a good memory support for preparation for their doctor/medical care visit. It assists people with chronic medical conditions as well as healthcare professionals to see the relationship between symptoms, side effects, treatment and lifestyle. Ne-

vertheless, there were also disadvantages such as the fact that it is difficult to analyse and time-consuming to log.

Nine people have been interviewed focusing on what self-collected health data means for them, what different variables of data they make note of and/or log and what they measure. 72 different variables within self-collected health data have been identified, from interviews and articles.

The identified variables are divided into four groups:

- Measurements – variables measured with available products
- Self-assessments – variables assessed by the indivdual that are not measureable
- Estimation of measurements – estimation of measureble variables
- Self-developed tests – variables measured with tests developed by the individual (sometimes with inspiration from research or other individuals)

A survey with a questionnaire has been carried out, as a student project, at the University of Gothenburg. 188 people responded to the questionnaire, about half of whom had one or more chronic diseases/illnesses. More than half of them collected health data about themselves at least daily or several times a day. Among those who were chronically ill, about one-third did so to supplement the healthcare they were receiving. The survey also asked about their feelings about sharing their health data, and it was found that most (84%) were in favour, however there was a significantly smaller proportion (67%) who were positive about sharing their medical records.

The report ends with a proposal for a structure of self-collected health data and how this can best be used to build services and assist individuals with their health challenges. It involves structuring data from various measurements, the individuals' self-assessments, and some healthcare data.

This report is aimed at people interested in health, self-care and healthcare. The primary target group is people with backgrounds in healthcare, patient representatives and people with informatics and technical interest.

Introduction

This report is about health data, specifically self-collected health data. The intention of the report is to deepen the discussion concerning health data by shedding more light on self-collected health data. An additional intention is to strengthen data-driven development to improve health.

The target group for the report includes people interested in health, healthcare, the healthcare system and information related to the above, and those involved in informatics. Both people with healthcare professions, health informatics professionals and people with technical training.

This report was written by Hanna Svensson on behalf of Lars Lindsköld's portfolio owner of Sweper, a part of Swelife. Hanna holds a Master of Science degree in Engineering Physics and Electrical Engineering and lives with type 1 diabetes and rheumatoid arthritis. With her professional background, she has excellent knowledge and experience in software development and system design. From her many years living with chronical conditions, she also has a solid experience from taking care of, structuring and storing self-collected health data.

Reading guidance

The report is divided into three main parts: background, results and discussion.

The *background* goes through the basic concepts to add a knowledge base to the remaining parts of the report. Read the chapters you need.

The results chapter is divided into the parts: *Health Data from the Author, Self-Collected Health Data – interviews, Self-Collected Health Data – questionnaire,* and *Articles Studied. Health data from the Author* goes through the author's health data, both self-collected health data and data in the healthcare system. *The Articles Studied* is a section where various published scholarly articles are reviewed and present the type of health data they use in their work. The two chapters on self-collected health data go through what people collect for their own health data and how they perceive this.

In the discussion *Self-collected health data* and a *Personal Reflection* is presented. The self-collected health data goes through various variables that are included in self-collected health data and how to sort them. The personal reflection touches on the question of evidence and one's own experiences.

After the Discussion a chapter on *Structure for Self-Collected Health Data* follows. It summarises and structures health data that has previously been touched upon and presents a model for this. The chapter has been written for people interested in informatics and technology.

The report also contains personal anecdotes which relate to the text.

Anecdote

"You'll have to go home and see what works for you."

I am constantly being asked to do this when it comes to how I should manage my diabetes. There are general guidelines and general knowledge to read about what to do. But the guidelines are so weak that they do not help in self-care, for example there are no guidelines on how I should keep my blood sugar in balance, just simply that I should do it. Information that is available for me to read to does not always match what is relevant for me, and it is conflicting with each other information or difficult to find.

"How should I try it out?" I ask. "You have to try out what works for you" the healthcare professional replies.

Over time, the the number of measurements have increased, from twice a day, to 240 times a day. The possibilities to test out what might work has exploded. What affects my glucose levels is hard to measure. It's about what I eat, how much I eat, when I eat, exercise, everyday exercise, stress, menstruation, and more. Attempting to find my way through this jungle of variables, data and information, and find what worked for me is complicated.

– Hanna Svensson

Definitions

Self-care: Medical self-care the ability of individuals, families and communities to promote health, prevent disease, maintain health, and to cope with illness and disability with or without the support of a healthcare provider. (WHO, 2019)

Artificial intelligence: The ability of computer programs and robots to mimic the natural intelligence of humans. This refers primarily to cognitive functions such as the ability to learn things from past experiences, understand natural language, solve problems, plan a sequence of actions, and to generalise.

Tracking/Self-tracking: To systematically measure or assess information about oneself, diet, health, activities or similar elements, with the purpose of finding behaviour patterns that can be adjusted to improve one's physical and mental well-being.

Lead patient or e-patient: A patient (or someone close to them) who uses their own knowledge and extensive experience to improve their own healthcare situation (or that of a person close to them) and also works to improve the healthcare system to make it better and safer for others. In other words, individuals who are equipped, enabled, empowered and engaged in both their own care but also at societal level. (Riggare, Krohwinkel, Lindqvist, & Conning, 2020)

Individualised medicine: Clinical, therapeutic and diagnostic procedures for optimal treatment of and illnesses based on the individual's activities, preferences and response to medication.

Health Data: Data, related to the health of an individual or group of individuals.

Self-Collected Health Data: Health data that an individual collects and records, either in a system or in their own memory. It concerns both measurements and assessments.

Quantified Self: An international community of users and developers of self-tracking tools that share an interest in self-awareness using numbers. (Quantified Self, 2020)

Background

This chapter goes through the basic concepts to add a knowledge base to the remaining parts of the report. Read the chapters you need.

The chapters are *Health*, *Self-Care*, and *Data and Artificial Intelligence.*

Health

Health is built up by several different components. Behaviour and lifestyle are a big part and what the individual can most easily influence, see Figure 1. Healthcare is another of these, but much less so. According to an American study, only 10 percent of our health is estimated to be affected by healthcare (Schroeder, 2007). Thus healthcare is necessary but not sufficient to achieve good health.

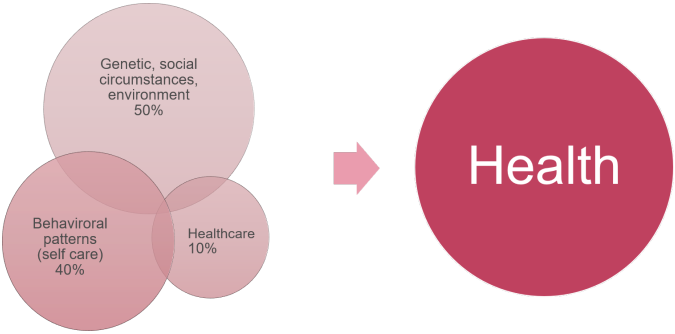

Figure 1 What affects health and how large are the different parts in relation to each other. Health is measured here with premature death that might have been able to be avoided. (Schroeder, 2007), adapted

Self-Care

Self-care is about what the individual does and can do to contribute to his or her own health. There are various different opinions how to define self-care. This report uses the World Health Organisation (WHO) definition. It opens up to allow medical self-care to be the basis of the work with one's own health and starts in people's capabilities and autonomy (Riggare, Krohwinkel, Lindqvist, & Conning, 2020). This definition is also used in Region Stockholm's Strategy for Self-Care (Region Stockholm, 2019).

> *"Self-care is the ability of individuals, families and communities to promote health, prevent disease, maintain health, and to cope with illness and disability with or without the support of a healthcare provider."*
> *– World Health Organization (WHO, 2019)*[1]

The Swedish National Board of Health and Welfare is the public authority that governs how the Swedish healthcare system should define self-care. They take a different approach from the WHO. They define self-care as:

> *a healthcare measure that a licensed healthcare professional has assessed that a patient can perform themselves."*
> *– National Board of Health and Welfare (Socialstyrelsen, 2009)*

This definition does not take advantage of the patient's own strengths and assets, which is why we choose to use the WHO definition in this report.

Data and artificial intelligence

What is data?

Data is, for example, measurements or answers to questions. It can be quantitative or qualitative. Quantitative data include measurements, metrics, figures and information that can be categorised. In the sentence "The person's body temperature is 36.7 degrees C" is "36.7" data and the variable measured is body temperature.

Qualitative data is, for example, a continuous text or a recor-

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[1] *From (Riggare, Krohwinkel, Lindqvist & Conning, 2020)*

ded interview. The sentence “It is very difficult to find information on this website” is an example of qualitative data.

Data, Information, Knowledge, and Wisdom

In this section, we walk through how we build information, knowledge, and wisdom based on data, see Figure 2.

Data – is symbols, signals, facts or observations.

Information — is data that has been given context, for example by querying and answering questions using available data.

Knowledge – is information that has acquired a meaning, a mix of experiences, information and insights.

Wisdom – is insights created from knowledge.

> *Typically information is defined in terms of data, knowledge in terms of information, and wisdom in terms of knowledge.*
> *– Jennifer Rowley (Rowley, 2007)*

Depending upon the perspective one has concerning what data is, one obtains different information and knowledge out of it.

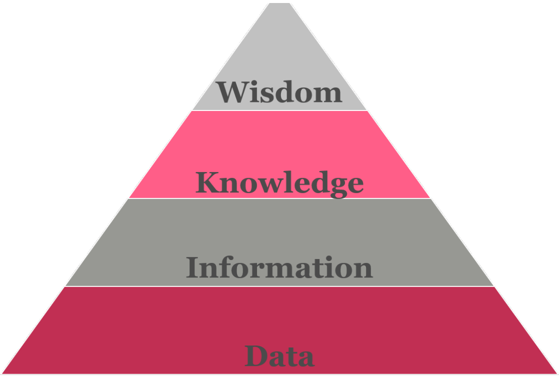


Figure 2 Data creates information, which creates knowledge, which in turn can lead to wisdom. (DIKW_pyramid, Wikipedia, 2020)

From a personal perspective, data may be, for instance, blood glucose, which in turn provides information about how blood glucose varies, and it can then provide, together with other information, knowledge about what affects it and how to adjust insulin dosages.

Artificial Intelligence

Artificial intelligence is usually abbreviated as “AI” and can be said to be computerised intelligence. It can be described as the capability of computer programs and robots to mimic the natural intelligence of humans and other animals. Primarily cognitive functions, such as the ability to learn things from past experiences, understand natural language, solve problems, plan a sequence of actions, and to generalise.

Systems with AI can solve different problems with varying degrees of independence (Cognilytica, 2019). Artificial intelligence has been around for a long time; the first neural networks, which are a method of AI, were described back in the 1950s (Wikipedia, 2020). The reason it has received such a boost in recent years is the development of AI algorithms, i.e. how to calculate and technical development of sensors and higher computational capacity.

ARTIFICIAL INTELLIGENCE AND DATA

A distinctive feature of systems built with AI is that they need to train on examples/data. For example, it may be that the system train on a lot of X-ray pictures of broken bones and then be able to decide if a future picture is an X-ray of a fractured bone or not.

> *Data is the new oil*
> *– Clive Humby*

In several contexts, there is talk that data is the “oil of the new age” (The Guardian, 2013). It seeks to make data a raw material, a commodity, that can be used very powerfully and that has great potential to solve problems that are difficult to solve otherwise. It is thanks to the availability of data that progress is so fast in our times.

Results

The results are presented here in four parts: P*ersonal Health Data from the Author, Self-Collected Health Data – interviews* and *Self-Collected Health Data – questionnaire,* and ends with *Articles Studied divided into a self-care focus and professional medical care focus.*

Personal Health Data from the Author

I went through all the health data about myself for one year, 2017. I divided health data into two parts: my self-collected health data and healthcare data. Healthcare data in this context is health data about me that exists within the healthcare system. For the self-collected health data, I have included measurements and self-assessments. I made related to my diabetes, my rheumatoid arthritis and my mental health. I include here measurements of glucose levels, continuous measurements of glucose levels, the basal meal insulin I take and the medication that I eat.

For healthcare data, I've included my medical records and the results of lab tests. I would also include here X-rays and eye photos if they had been applicable that year.

I've modelled each dataset as a point, whether it's an unstructured note in the medical record or a glucose level. This is of course a simplification — the note in the medical record contains more information than a glucose level — but because a note is unstructured, it becomes more difficult to use with automatic data processing.

The overall health data amounted to about 95,900 points this year. Of these points, about 26 were healthcare data, see Figure 3. Roughly estimated, based on this, it can be said that about 1 percent of my personal health data is in the healthcare system. The rest, more than 99 percent, exists only in my self-care.

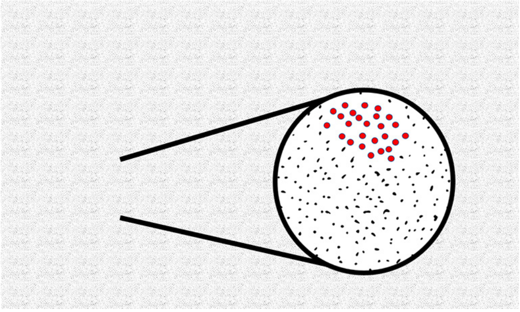


Figure 3 Personal Health Data from the Author. Each point represents an information point, such as a blood test or a note in my journal.

Self-Collected Health Data – interviews

Nine people who are experienced patients, referred to as e- patients or lead patients were interviewed about what information and data they use to achieve good health and manage their own healthcare. An open question was put to all persons. *What kind of information/data do you collect as part of your self-care?* and then various follow-up questions were asked to identify each person's sources of data/information and variables. The term "variable" refers to a personal quantification of experiences/emotions, a self-assessment or results from a measurement. Examples of personal quantification include how stiff one feels themselves to be.

Specifically, it was asked what different variables the respondents assessed for self-care purposes, what was measured, how many medical records there were and how many lab values were measured. The objective has been to identify different variables, not see how common they are.

Measurements and assessments

Several different things were discovered that were measured with various instruments to obtain values. These instruments/healthcare tools are sometimes common consumer products paid for by the person themself, and sometimes instruments prescribed by healthcare. See Table 1 for an enumeration of which variables are measured.

Many variables that people talk about cannot be measured, but rather are assessments of different sensations. It is, for example, about how stiff one feels they are. These are usually assessed only on an arbitrary scale and are not logged anywhere. See Table 2 for a enumeration of which variables are assessed. When it is assessed, it is rarely logged. Often they only use the information at the time when they estimate it.

Table 1 Different symptoms and signs that the respondants measuered.
Weight
Body temperature
Blood pressure
Glucose levels
Continuous glucose measurement
Activity
Food intake
Sleep
Exercise
Lab results values
Step
Heart rate measurement
Measurements using a smartphone sensor

Table 2 Different symptoms and signs that the respondants assessed
How am I feeling?
Fatigue
Vision
Emptying of the bladder/bowel
Perception
Soreness/pain
Sore throat
Feeling fevered
Swelling
Stiffness
Tightness in one's head
Calories

One of the interviewees pointed out the difficulty of having these endpoints constant, that the reference values shifted with time. This means that the answer to “How well have I slept?” can be equal between two different occasions but that does not necessarily mean the same quality of sleep, simply because one might get used to poorer sleep and even the reference values change.

One of the interviewees pointed out the advantage with the individualized quantity and the personal assessment of they created. This was how that person could capture what was important for him/her.

Some things that the interviewees specify are also things that can be measured but that one chooses to estimate instead. For example, it can be about how hard a workout is – which can also be measured by heart rate – or dietary choices and how much one eats. We have not made any distinction in the list between what could be measured and what is estimated, as this is a bit different among the interviewees.

Many of the interviewees log or save their measurements, estimations or assessments. Those who do, do so in a paper log or a spreadsheet (such as Google Forms). One of the interviewees wrote a diary to document everything.

Self-developed tests

A self-developed test is a test procedure developed by the user, either completely by themself or with knowledge from other test procedures, persons or publiched research and articles. Two self-developed tests were identified. They are called the laptop test and the tapping test here.

Table 3 Various self-developed tests used by the interviewees.

Tapping test Laptop test

The laptop test seeks to measure the inflammation of the gastrointestinal system. In this test, the person places a weight on the stomach to see the level of pain. Always using the same weight produces a result that the person experiences more reliably. The pain is a sign of inflammation of the abdomen, and occurs according to the person before other symptoms appear. The person who does this test uses their laptop as the weight, hence the name of the test.

Tapping tests are common tests to evaluate motor function with instances of various diseases and illnesses. It has been refined here to fit with measuring Parkinson’s symptoms with available equipment. The test is to see how many times one can click, with the same finger, on a smartphone screen for 20 seconds. This was partly described during interviews, but more information has been gathered in (Riggare & Hägglund, 2018).

Anecdote

“How are you feeling?”

When the rheumatologist asks this question, it is part of an assessment. What she wants to know is how I feel, and have been feeling since I last saw her, in regards to my rheumatic disease. In order to obtain the answer, follow-up questions are usually asked, a little more detailed questions. From the rheumatologist, it is often asked: “Are you stiff in the morning?” I remember that time when I had no answer! I didn’t know the answer to that.

cont. next page

> I usually note when I get out of bed in the morning whether or not I am stiff. It's simply much harder to get up when I'm stiff, and the first steps I take can be stumbling. But then I forget everything about the stiffness and simply push forward during the day. I rarely stop before lunch and think about whether I am stiff or not, because the stiffness never stops me in my office work or in my leisure activities.
>
> I was asked several questions about this; apparently there was a box where she needed to fill in what time I wasn't stiff anymore. I felt pressured to say something, even though my memories of stiffness in the middle of the day were basically non-existent.
>
> – Hanna Svensson

Self-Collected Health Data – survey

On behalf of Swelife and under the supervision of the author of this report, a survey of self-collected health data has been carried out by students at the Systemvetenskapliga Programmet/Systems Science Programme at the University of Gothenburg (Lemonte, Andreasson, Dahnberg, & Kullbo, 2020).

The questionnaire was sent out to students at the University of Gothenburg, people in the e-patient network and disseminated via social media. 188 responses were received. The questions in the questionnaire were designed after a feasibility study of material from the Quantified self-community.

Self-Collected Health Data

Respondents to the survey indicate that variables such as sleep, steps, and exercise are the most common to measure, see Figure 4. The majority of survey participants measure or collect health data daily, or at least every other day. 15 percent of participants measure their health data several times daily. See Figure 5 for more details.

When it comes to which methods and measurement tools are used to save the results of measurements and assessments, mobile applications and body-worn devices are at the top. See Figure 6 for details.

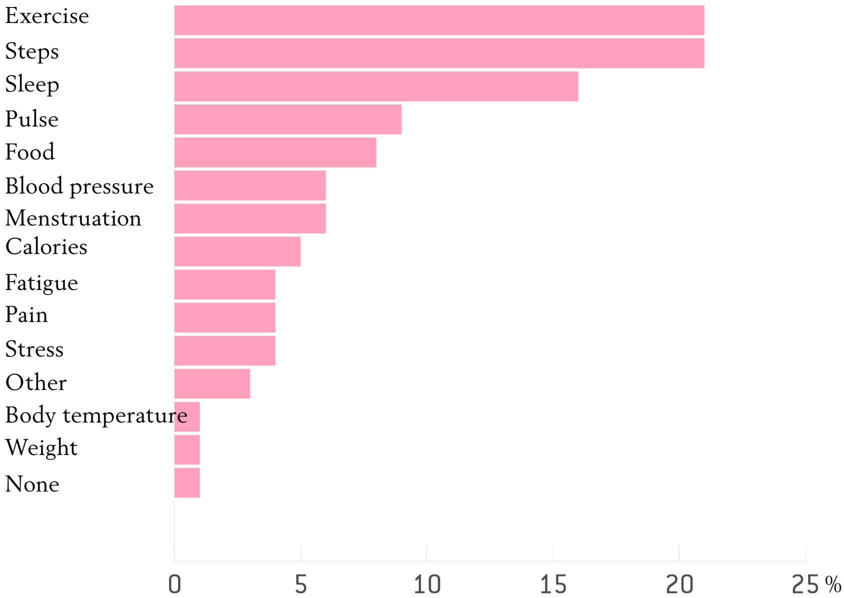


Figure 4 Compilation of questionnaire. Different variables in the self-collected health data (Lemonte, Andreasson, Dahnberg, & Kullbo, 2020)

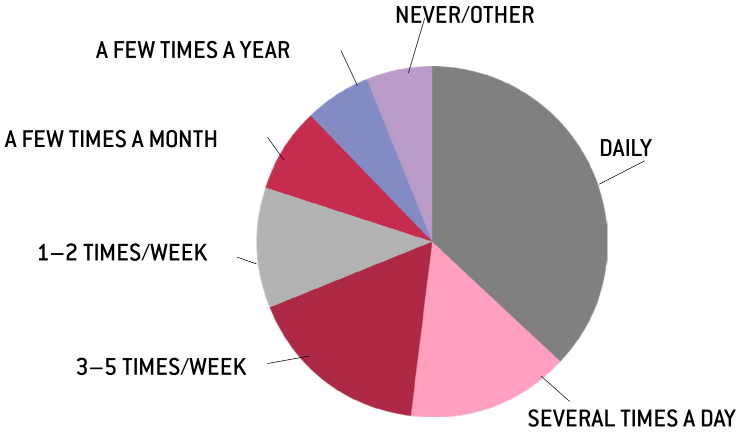


Figure 5 Compilation of questionnaire. How often people collect their own health data (Lemonte, Andreasson, Dahnberg, & Kullbo, 2020)

Drivers

Several different driving forces were identified, but in the survey, there were no particular driving force that was more common than any other. The driving forces were *Healthier Lifestyle*, *Prevention*, *Exploration/Curiosity*, *Improving Performance*, *Solving Health Problems*, and *Supplementing healthcare*. They were distributed fairly equally between people with or without chronic conditions, except the driving force *Supplementing healthcare*.

The survey showed a difference between people with chronic/long-term conditions and healthy individuals, and that was the driving force to supplement professional medical care. For people with chronic or long-term conditions, that driving force was 29 percent, compared with 3 percent in the healthy people who responded.

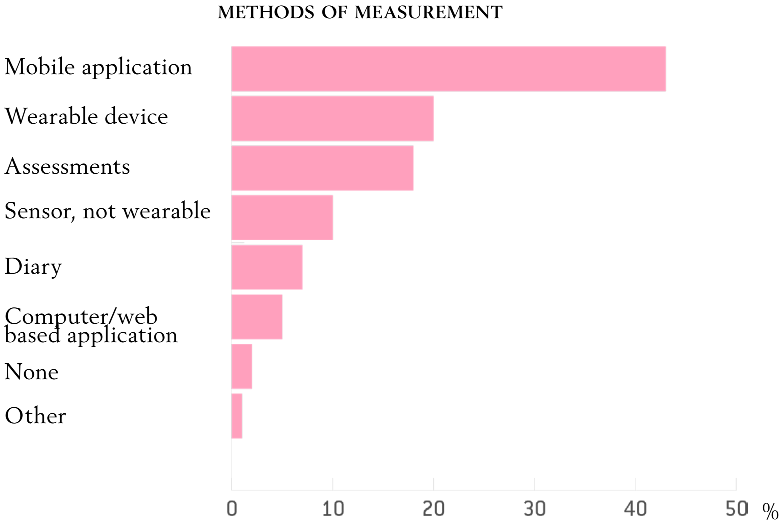


Figure 6 Compilation of questionnaire. Distribution of measuring tools/methods. (Lemonte, Andreasson, Dahnberg, & Kullbo, 2020)

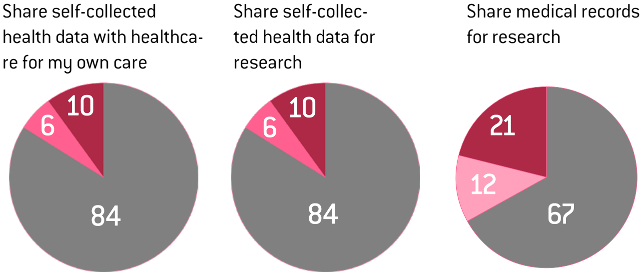
Sharing health data

Individuals mainly have a positive view towards sharing their health data with healthcare and for research purposes. This has also been shown by previous surveys (Nilsson Vindefjärd, 2018).

Our survey shows the same thing, however it also shows a difference in attitude sharing self-collected health data and medical records. 84 per cent of respondents are willing to share their own collected health data for research purposes or in their own care. When it comes to sharing medical records for research purposes, only 67 percent of respondents can imagine doing so, see Figure 7. The reason that fewer people are willing to share their medical record is that it consist of others interpretations about them, and the fact that they can't influence what is written or correct it if wrong.

Reasons for wanting to share data in ones own care include a vision of obtaining improved treatment, personalised/customised care, better treatment and quality assurance. For research purposes, reasons are that they want to help others, driving the research forward and find new solutions, medications and causes of diseases and illnesses.

As a reason not wanting to share self-collected health data in their own care context is that they don't believe the healthcare to be interested in it. There are also a concern that it may be shared with third parties. Anonymisation is mentioned when sharing both self-collected health data and patient chart data and it is considered important that the data one shares is anonymised (pseudonymised, author's interpretation).



Share self-collected health data with healthcare for my own care

Share self-collected health data for research

Share medical records for research

Figure 7 Compilation of questionnaire. How many people are willing to share health data and/or medical records for research or in their own care?

Articles Studied

This chapter presents a few published articles dealing with data, information, measurement and AI in self-care and healthcare. The purpose is to study the articles and identify which different variables the authors describe and use in their further processing of data, whether using AI or by people.

The articles that have been studied can be grouped into two categories: articles with self-care focus and articles with a healthcare focus.

Self-care focus

First comes the category of articles that all start out from the patient and his/hers self-care, with various elements of support from healthcare.

A research group, affiliated with Gothenburg Centre for Person-centred Care – GPCC, has studied the treatment of hypertension and how it changes with the help of self-monitoring. They describe the self-care aspect well, but are not so good at automation and automatic analysis (Hallberg I, 2014) (Bengtsson U, 2014). Within the project systems have been created to collect and measure different variables in self-care, thereby giving patients better possibilities for self-care. The healthcare professionals then assists the patient to interpret their data to find correlations between different variables and lifestyle as well as taking medication. The variables that are relevant to measure and look at are determined together with patients and healthcare professionals at the beginning of the project. The variables measured are shown in (Bengtsson U, 2014) Table 4 and Table 5.

The research group investigates the driving forces for the patients for collecting health data and they indicate here a need to see the relationship between symptoms, side effects, treatment and lifestyle. One point of view that emerges from the articles is that it is difficult to interpret the graphs and see the correlations that exist.

Compared to the knowledge pyramid, page 10, their data source is the patient's own measurements and assessments.

Another research group, at the Karolinska Institutet, is investigating self-measurements/self-tracking for people with Parkinson's disease.

Measuring or assessing is not important in itself, but what is measured or estimated comes into focus. Tracking, in this case the same as measuring and assessing, is also a strenuous job for the individual and it is important to know both about the advantages and the disadvantages for the individual. This is reflected in an article on self-tracking for people living with Parkinson's disease (Riggare, Scott Duncan, Hvitfeldt, & Hägglund, 2019). Therefore, it is important to be especially careful when looking at what should be tracked at the individual level. It is important to primarily focus on what is important for the particular individual. It is also important to measure in an appropriate way and reflect on the sources of error that are present (Riggare, Scott Duncan, Hvitfeldt, & Hägglund, 2019). What different individuals collect or assess is shown in Table 6. The most common variable tracked is the intake of medicine, for the purpose of optimising exactly when the medicine is to be taken. Stress, diet and sleep are second most common (Riggare, Scott Duncan, Hvitfeldt, & Hägglund, 2019).

Table 4 Symptoms and habits to follow up in instances of high blood pressure (Bengtsson U, 2014)
Dizziness
Insomnia
Depression
Food
Palpitations
Stress
Tobacco smoking
Using snus
Fatigue
Swollen ankles/edema
Everyday exercise
Headache
Anxiety/concern
Exercise
Frequent urination
Xerostomia (dry mouth)
Alcohol intake

Table 5 Measurements to follow up on high blood pressure (Bengtsson U, 2014)
Blood pressure
Waistline
Weight
Respiratory rate
Glucose levels
Blood lipids
Pulse

The only article that deals with how often people measure is the article on self-tracking for persons living with Parkinson's (Riggare, Scott Duncan, Hvitfeldt, & Hägglund, 2019). Here, 49 percent of respondents said they used some digital technology for logging (computer, sensor, smart watches or something similar). Fifty-six percent used a pen and paper, and 74 percent of respondents used their own memory without making notes.

The article also examines what the benefits and driving forces behind self-collected health data are. For many (73 percent), self-tracking is a way to be able to understand the correlation between medication intake and symptoms, and how the symptoms of the illness fluctuate over time. Self-tracking was considered an excellent support for memory in preparation for their neurologist visit and to be able to give the neurologist an accurate picture of the illness.

Table 6 Aspects tracked by people living with Parkinson disease (Riggare, Scott Duncan, Hvitfeldt, & Hägglund, 2019)
TTime of taking medication
Type of medicine
Physical activity
Sleep
Stiffness
Fatigue
Tremors
Dyskinesia
Medical side effects
Slowness of movement
Stress
Problems walking (freezing gait)
Mood/depression/anxiety
Problems with the stomach
Diet

Another article summarises various different measurement techniques in instances of diabetes, both type 1 and type 2. They also describe what it can look like when we move from a world where patients are characterised by only a few measurements of glucose levels and lab test, to a world where patients, professionals and researchers can simultaneously take several key variables at thousands of points in time into their analysis. (Fagherazzi G, 2019). An illustration of possible measuring units can be seen in Figure 9.

They point out the lack of possibility for the various connected devices to communicate with each other and that this results in a barrier to effectively use the different devices.

Table 7 shows what can be measured according to them.

Table 7 Measurements and devices that can be used in instances of diabetes (Fagherazzi G, 2019)
Glucose levels
Glucose measured in eye fluid
Blood pressure monitor
Smartwatch (activity, sleep, blood sugar level, heart rate, localisation)
Smart socks (temperature, inflammation, infection)
Continuous glucose measurement
ECG (palpitations)
Apps (control of connected devices, medical records, social media, patient communities)
Weight

Healthcare focus

Halmstad University together with Region Halland have been successful in the field and have several articles on automation of professional medical care and decisions in this area. They use data from electronic medical records. The articles have a strong healthcare focus in the issues and questions they raise, and in which data sources they choose. One article describes algorithms that

predict the risk of death 30 days after an emergency visit (Blom MC, 2019) and in another they estimate the risk of re-admittance due to continuing cardiac problems (Ashfaq A, 2019). See Table 8 and Table 9 to see which variables are used.
The data they use comes from electronic medical records and is represented by a sequence of medical visits. The data for each visit consists of two parts: demographic information (for patients and caregivers) and the patient's clinical condition (Ashfaq A, 2019). Demographic data consist of age, gender, location, type of visit and related. The clinical condition is represented by clinical codes and values associated with diagnoses, procedures, laboratory results, vital signs, and medications.

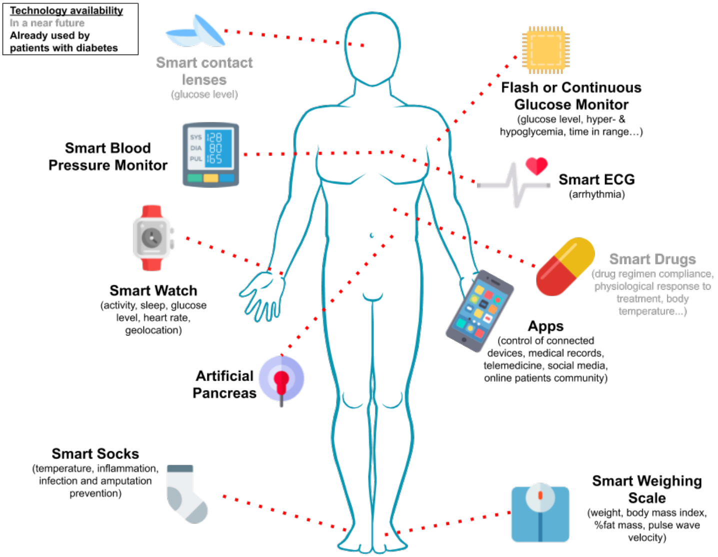


Figure 9 Diabetes Treatment and Monitoring Units (Fagherazzi G, 2019)

In these articles, it is the medical record systems that are the data source and the smallest element for building knowledge and wisdom. Compare with the knowledge pyramid on page 10.

Table 8 Data input to calculate risk of death within 30 days (Blom MC, 2019)
Gender
Arrived by ambulance
Visit after a physician’s referral
Triage priority 1
Triage priority 2
Departing in contradistinction to medical advice
Discharged at night
Discharged during the weekend
Discharged during the summer
Discharged during the winter
Gender of the treating physician
Junior or senior, treating physician
Prescribers, physician or not physician

Table 9 Data input to calculate risk of re-admittance for hospitalisation (Ashfaq A, 2019)
Age
Gender
Adherence to taking prescribed medication
Code for procedures performed
Length of current stay
Type of visit
Charlson Comorbidity Index (CCI)
Number of previous emergency room visits
Number of previous hospitalisations
Number of previous clinic visits
Total length of all stays
Diagnostic codes (ICD-10-SE)
Medication (ATC)
Lab results (with abnormal results)

Discussion

This chapter begins with a personal reflection concerning personal experience and published studies. An analysis of self-collected health data is then presented based on interviews and surveys conducted.

> *The society-at-large needs to move towards a transition from medical treatment to health, when disease/illness is present.*
> *– Sara Riggare*

Own experience and published studies

My experiences help me understand my body works and what is important for my quality of life. Medical knowledge and published studies explain and investigate how bodies function in general; it is a kind of average body that is described. Generally, the strength of evidence lies in how many people have been involved in the study. While the strength of my own experiences lies in how many times I have experienced or tried out something.

We obtain different knowledge from medical studies and our own experience. For example, it is difficult to understand from ones' own experience how various different actions affect one's lifespan or how different medications work inside the body, but I certainly can learn about how my own body reacts to exercise.

My own experiences of my health are described by both stories and many measurements/assessment. It is my experiences, combined with the results of lab tests and medical examinations, that show how I am affected by what I do (and don't do), what I eat, and by my medications.

For maximum health, for me as an individual my experiences need to be combined with knowledge in medicine and nursing.

Anecdote

A successful example of combining research and one's own experiences.

A few years ago, I had trouble cycling to work, about 8 kilometres. I almost always had low glucose levels and had to stop to eat and rest. I tried out everything I and my then-diabetes

cont. next page

doctor could think of (which was basically only to lower the insulin doses before I started cycling).

But then I met with a nutritionist who suggested that I should instead eat raisins when I cycled to work. A suggestion that seemed possible to test out. His idea of this came from his research in and knowledge of sports nutrition. He gave me another tool in my toolbox when dealing with my glucose levels. It was a tool that actually turned out to be helpful to me. Finally I was able to cycle to work without getting low glucose levels.

- Hanna Svensson

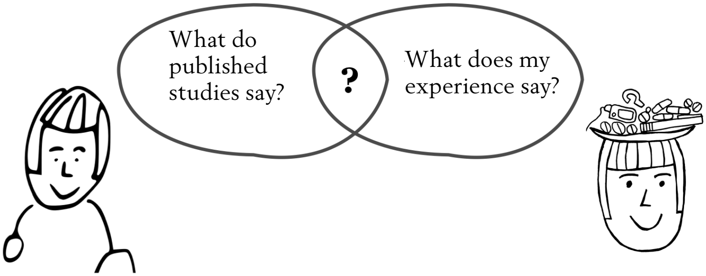


Figure 10 When my own experience meets professional expertise-based knowledge – that's when I as an individual can get so much out of professional medical care with the aim of maximising my health.

Self-Collected Health Data

The largest subset of health data for the individual is self-collected health data. In the report, 72 different variables of self-collected health data are presented, see Table 13 on page 31. Based on these, four groups have been identified, see the summary Table 10.

MEASUREMENTS

Measurements of physical quantities and calculations, and analyses of measurement data. Examples include readings of body temperature and totals from step counting.

ESTIMATIONS OF MEASUREMENTS

Estimation of measurements are subjective estimates of things that can be measured. It may include how hard a workout is (which can also be measured by heart rate) or dietary choices and how much one eats (which can be measured by a weight scale and calculated based on known nutritional content).

Table 10 Groups of self-collected health data

Measurements: What one can measure with an accessible product

Assessments: What can be assessed and cannot be measured

Estimation of measurements: What can be estimated but also can be measured

Self-developed tests: What is measured using methods developed or refined by the user themself.

ASSESSMENTS

Assessments are data on subjective quantities that cannot be measured. It may be about stiffness, fatigue or how one feels.

Assessments can be made on a scale of defined endpoints by the individual. For example, “Not stiff at all” — “So stiff that I can’t get out of bed.” Assessments are made either on a continuous scale (VAS[1] scale) or a discrete scale (NRS[2] scale) with endpoints that is decided by the individual.

SELF-DEVELOPED TESTS

A self-developed test is a methodical way to quantify an assessment or a measure of a physical quantity that is difficult to measure by standard means. A self-developed is a test that a person has developed to be able to measure something on themself in a more objective way than an assessment.

Table 11 Groups of ways to log and record self-collected health data

1. Remember
2. Manual logging: in one’s notes, Excel worksheet, or specific mobile app
3. Automatic logging using the measuring equipment/ devices

How to save and log?

In order to be able to make data available afterwards for analysis, it needs to be saved. The persons interviewed and respondants to the questionnaires have done in several different ways.

Three main groups for this were identified, see Table 11.

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[1] *VAS. abbreviation for Visual Analog Scale*

[2] *NRS. abbreviation for Numeric Rating Scale*

In addition to these three groups, there were also some who wrote diaries to save their information, but since this is an unstructured way of documenting, it is not addressed here.

Things to keep in mind: When people make an assessment of different symptoms or everyday events, they rarely save them. The data is used there and then and when one wants to do an analysis afterwards, the data is found only in the memory of the person who made the measurement or assessment.

Manual logging: The next group is something that one saves in a app for a specific type of data, in their own spreadsheet or in another computer or web-based application.

Automatic logging: Automatic logging is when the measurement tool, such as an activity tracker or glucose meter, automatically logs its readings. The measurements can usually be visualised in a web application and can sometimes be downloaded for one's own data processing.

All three variants are good, what works best depends on different needs and uses. Manual logging is time-consuming. Automatic logging can be technically complex. Remembering is difficult and there is a lot of data that disappears because one forgets. Data that most likely would be able to provide more knowledge to the person about their lifestyle and treatment.

Driving forces, benefits and problems

A majority of those who collect their own health data are doing so for the purpose of achieving a healthier lifestyle or preventing unwanted health conditions. Those who collect their own health data are generally health conscious and desire to improve their own health.

Some of the respondants talks about problems with tracking and self-collected health data. One problem is that it cause one to focus on the wrong things, namely what is easy to measure. Another problematic situation may be that one's benchmark moves over time and that it becomes difficult to measure or assessment this reference point. The change in reference point can lead to a false sense of security when assessments are constant, despite changes in health. What and how to measure is therefore very important.

Self-collected health data, with symptoms that one registers, and sometimes save, are often the basis for answering questions during a healthcare visit. Answering questions about one's health and everyday situations is not easy, and therefore the quality of these answers is not always good.

How often and how much does one measure?

The frequency with which measurements are carried out ranges from once a month to several times a day. For continuous measurements such as blood glucose readings, it can be up to 250 times per day and for heart rate monitors approximately 1440 times per day.

Based on the interviews, analysis of the amount of self-collected data related to the amout of healthcare data was made for the interviewees. The analysis was performed in the same way as for the author, see page 9 in the chapter Personal Health Data from the Author. It turns out that for these people too there is a lot of data in self-care and less in healthcare, see Table 12. The basis is small and the method is not so developed, but the figures show the tendency that the absolute majority of an individual's health data is not found in the healthcare system.

Table 12 Data sets in self-care and professional healthcare for the persons interviewed

	All care	Healthcare	Part healthcare
Hanna	95 898	60	0,06%
Person 2	458	5	1,09%
Person 3	20 107	32	0,16%
Person 4	444	79	17,79%
Person 5	1 682	1,5	0,09%
Person 6	1 480	20	1,35%
Person 7	11 033	23	0,21%
Person 8	35 044	4	0,01%

Structure self-collected health data

To deal with a massive amount of data, structure is required. This chapter presents a structure for self-collected health data. The target group for the chapter is people interested in informatics and it is somewhat deeper technically than the previous chapters.

A useful, adaptable and clear information structure for data outside the healthcare system can contribute to new tools, which in turn can contribute to better follow-up and more individualised medicine. It increases the opportunities for each person to solve their health challenges, with or without support from healthcare. In the long run, these efforts can also create a better basis for anamnesis and description of symptoms by improving and simplifying tracking.

Self-collected health data spans several different diagnostic areas, just as individual health challenges often do. Therefore, a structure is presented here that can be used regardless of the area of diagnosis, and also for people without chronic conditions.

The structure consist of a general model that has to be configured and results in a personal model.

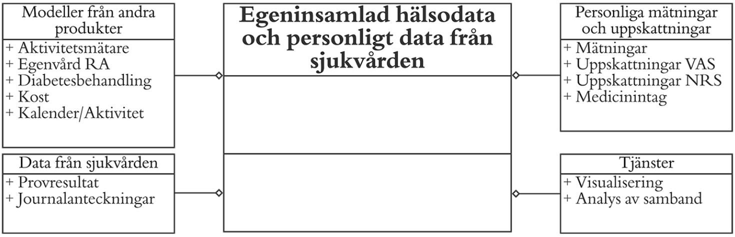

Figure 11 Overview of the general model of an individual's health data.

Models

A general model for the individual's health data, consisting of several parts, is presented here. An overview can be seen in Figure 11.

It consists of four parts:

- Model for personal measurements, assessments and estimations
- Existing models for products on the market
- Model for personal healthcare data
- Model for connection to services

Personal measurements and assessments

The variables tracked by measurement, estimations and assessments have similar metadata content and can therefore be modelled in a similar way. To see which variables have been identified in this report, see Table 13 on page 31.

The variables in the self-collected health data can be summarised in four groups, see Table 10:

- *Measurements*: What one could measure with an available product
- *Assessments*: What was estimated and could not be measured
- *Estimations of measurements:* What is estimated and could be measured
- *Self-developed tests:* What was measured using methods developed by the user themselves.

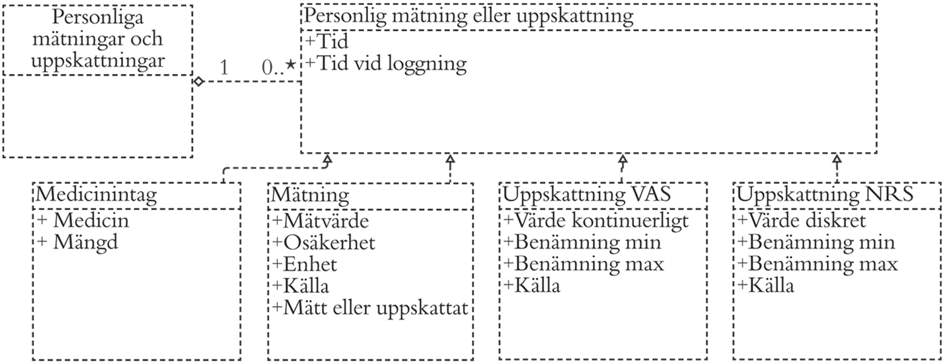

Figure 12 Graphs with classes to describe personal measurements and estimations

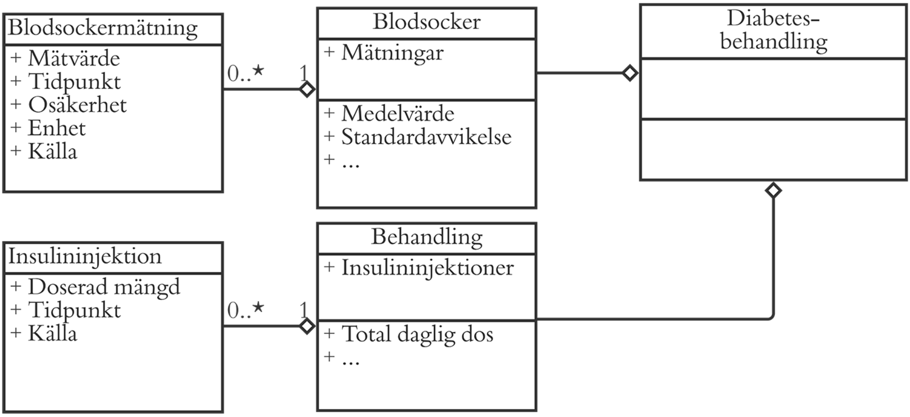

Figure 13 Diabetes data stored in self-care treatment and taking of specimens sampling

Based on the identified groups above and the fact that many people have talked about the importance of tracking their intake of medicines, both timing and quantity, the following four data types are suggested. These are sufficient to be able to model all self-collected health data.

- **Measurement**: *Measurements*, *Estimations of measurements*, and *Self-developed tests*
- **VAS estimation:** *Assessments*
- **NRS estimation:** *Assessments*
- **Medicine intake**

The measurements and estimation of measurements can be seen as the same type of data but with an attribute if it has been measured or estimated, as well as information about the unit of measurement and precision. The self-developed tests are the measurements.

The model for personal measurements and estimations can be seen in Figure 12.

Models for other products

The models that exist in products/devices or standards include, for example, activity bracelets, health apps, or apps for specific self-care. Presently these models are usually tied to one particular service, such as Google Fit or Apple Health, which calculates different health variables and shares their information with other health apps.

Many persons today already use products/devices, both software and sensors, for logging and measurement as part of their self-care. Therefore a new system, to be useful, needs to include data from pre-existing products/devices.

One example of how diabetes data is modelled in a product is shown in Figure 13. In order to be able to build a system that is useful, it needs to be possible for already existing products to be connected.

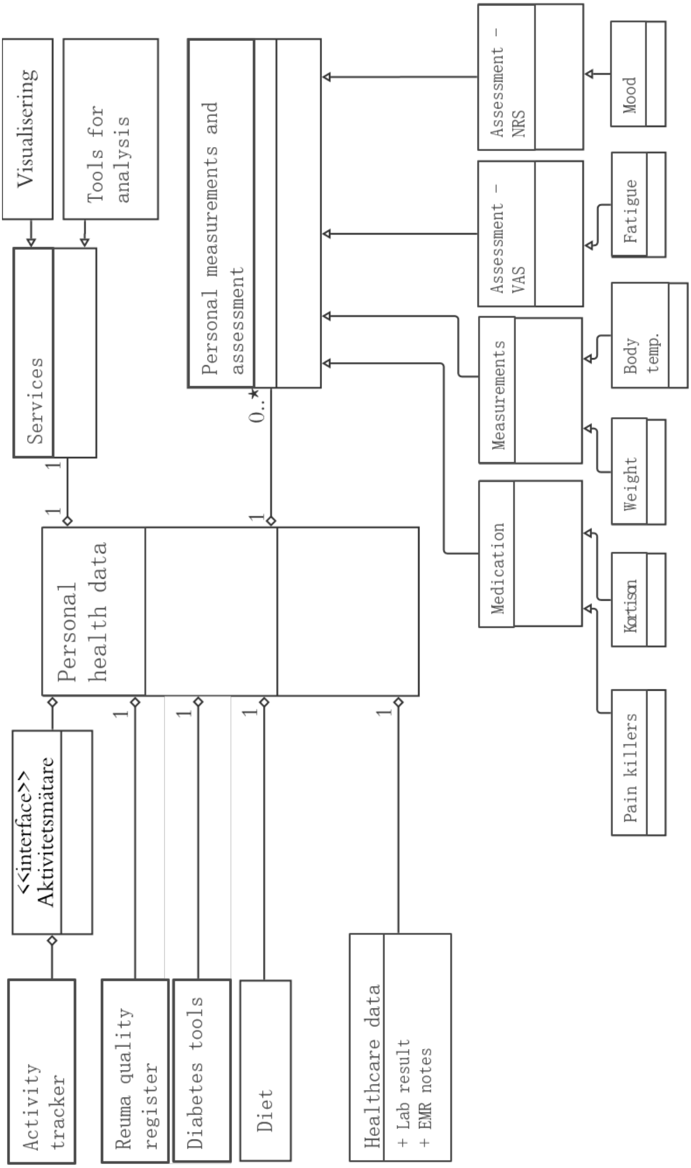

Figure 14 General model for self-collected health data and professional medical and health data. Examples of model for existing product, i.e. classes Activity Meter 1, Activity Tracker 2, Self-Care RA, Diabetes Data, Diet and Activity/Calendar, can be seen in Figure 13 above.

Figure 15 Flow chart for how to develop the personal model

General model

By combining the model of personal measurements and assessments with the mode and models of healthcare data and for services, a general, comprehensive model is developed. An illustration is shown in Figure 14.

Personal model

Considering that each person is unique and wants to track different variables, personal models are needed that contain what is important to the particular individual.

A personal model can be created by starting from the general model and then picking out what is important for the individual, both in terms of services and data content. Figure 15 shows a flow chart for this.

The value of the model for the individual is an improved structure of self-collected health data; that self-collected data can be gathered into one place plus that hopefully services that use data will be able to access the self-collected healthdata when used. The added value for society is that then there is a better basis for understanding the health of individuals, and conducting research and further development.

The hope is that this can lead to a link between *What studies say* and *What my experience says*. In the long run, I hope that it will lead to more care closer to the recipient in the form of self-care, a simpler collaboration between professional healthcare providers and individuals, and a better basis for research.

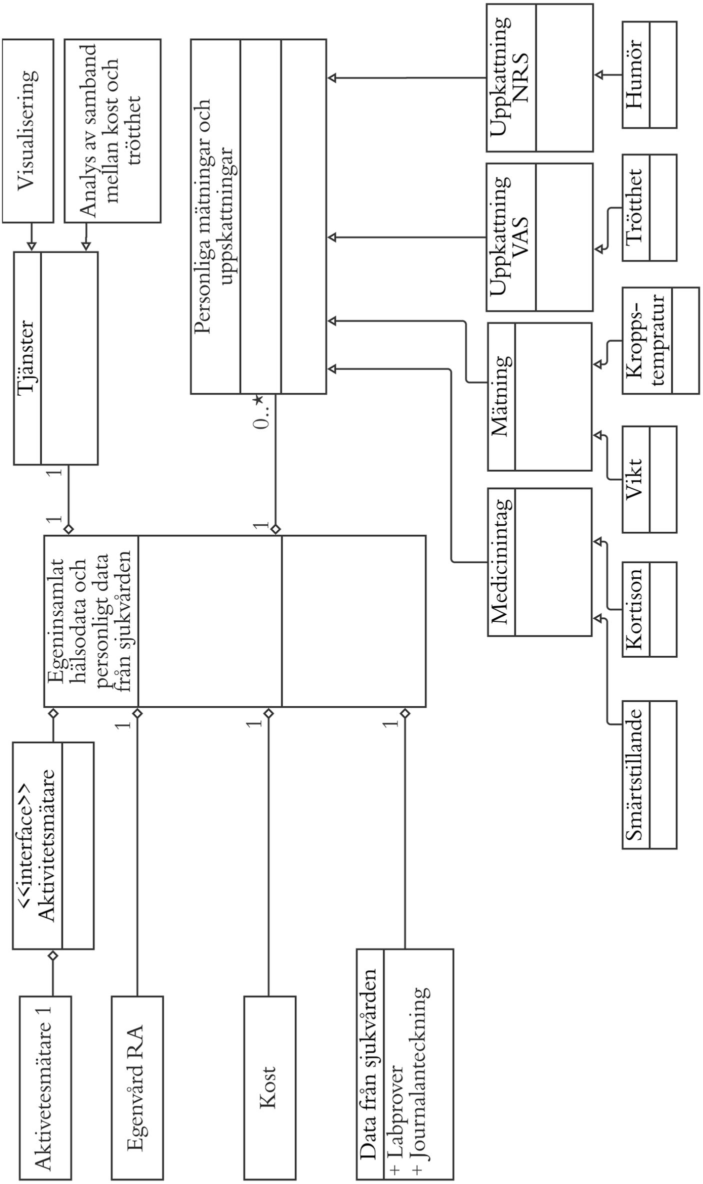

Figure 16 Personal model for self-collected health and personal data from the healthcare system

Continued work forward

The report seeks to increase the dialogue concerning self-collected health data from the perspective of the individual: How can self-collected health data be used to strengthen the individual's preconditions for good health, even in the vicinity of illness, and how can research based on health data be strengthened?

Without doubt, the availability of data that is self-collected will be of great importance and have a major impact on future innovations.

It is important that society-at-large develops clear guidelines for how and when individual data can be used. One example is Vinter, the Vinnova - Swedish Agency for Innovation Systems initiative, an innovation competition to establish services for people with type 1 diabetes. This could be a model for how an ecosystem of data management in healthcare could be developed together with individuals and industry.

This report has focused on relatively healthy, adult people with chronical conditions, and all perspectives have not been investigated. In the near future, we would like to see an extension with the following:

- Explore the needs of people receiving social care from municipal healthcare providers
- Explore the needs of people who are aged
- Explore needs for children and parents
- Broader basis from more people surrounding the importance of self-collected health data

In order to be able to use self-collected healthdata not only for the individual but also for society and research, the following points are seen as important:

- Develop an information model for self-collected health data.
- Implementation of a system for self-collected health data from several different sources.
- Establish a framework where self-collected personal health data can be aggregated and compared across multiple sources.
- Investigate if and how the self-collected health data relates to the symptoms described, diagnostic criteria, and other healthcare information.

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Appendix

Compilation of Variables

Compilation of different variables in self-collected health data.

Table 13 Compilation of different variables in the self-collected health data

Activity
Alcohol intake
Anxiety/concern
Blood lipids
Blood pressure
Body temperature
Calories
Continuous glucose measurement
Depression
Diet
Dizziness
Dyskinesia
ECG (palpitations)
Emptying of the bladder
Emptying of the bowel
Everyday exercise
Exercise
Fatigue
Feeling fevered
Food
Frequent urination
Glucose levels
Glucose measured in eye fluid
Headache
Heart rate measurement
How am I feeling?
Infection
Inflammation
Insomnia
Lab results values
Laptop test
Measurements using a smartphone
Medical side effects
Mood/depression/anxiety
Palpitations
Perception
Problems walking (freezing gait)
Problems with the stomach
Pulse
Respiratory rate
Sleep
Slowness of movement
Localisation
Sore throat
Soreness/pain
Steps
Stiffness
Stress
Stress
Swelling
Swollen ankles/edema
Tapping test
Tightness in one's head
Tobacco smoking
Tremors
Using *snus*
Vision
Waistline
Weight
Xerostomia (dry mouth)

Health Data

At the beginning of the report, health data is defined as "*Data, related to the health of an individual or a group of individuals,*" page 5. This chapter presents a more detailed and defined picture of what health data is. It is presented in two separate groups: *health data for the individual* and *health data for society-at-large*.

The reason for the division into these data groups is that they can be seen to respond to different types of problems and that the different parts are partly governed by different sets of rules and regulations. The majority of the health data for the individual is governed by the European General Data Protection Regulation (GDPR), while health data at the societal level is governed by other statutes and regulations.

Health data at the societal level also includes health data that is not linked to an individual, such as hospital bed occupancy and utilisation rates and weather data.

Data at the societal level can be used to solve problems at the population level. The problems can be likened to a navigation system that can guide drivers to the right address via roads with the least traffic on them. Personal-level data can assist the individual with their own health challenges, problems similar to systems that help the driver stay on the roadway and not drive into a ditch.

Both functions are equally important for being healthy or arriving safely, and it is when these levels can be combined that the personalised medicine is made possible.

Health data for the individual and for the society-at-large are shown in Table 14 and Table 15, below.

Table 14 Individual health data
SELF-COLLECTED HEALTH DATA
Training data
Self-measurements
Taking medication
Estimations
HEALTHCARE DATA
Patient chart data
Quality register
Biobank
PRECONDITIONS
Genetics
Socio-economic background

Table 15 Health Data for the Society-at-Large
HEALTHCARE DATA – THE SYSTEM
Staff
Coverage
Capacity
PRECONDITIONS FOR THE HEALTHCARE SYSTEM
Financial budget
Population
HEALTHCARE DATA ON INDIVIDUALS
Medical records
Quality register
Biobank
CONDITIONS OF THE POPULATION
Genetics
Socio-economic background
SOCIETAL DATA
Weather
Map information
Air pollution