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Visualization of Actual and Expected Trajectories for Stroke Patients

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Master of Science in Computer Science

Submission date:	June 2015
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ASSIGNMENT

The PAsTAs (PAtient TrAjectories, or "Pasientforløp") project is a five-year project that is analyzing what happens to chronically ill patients, as they are moved between their primary doctor, the hospital, and other services offered by the local government. Currently, the information about single patients is not coordinated between hospitals and other services, making it difficult to do research about what combination of services is best for chronically ill patients. In this project, data will be collected from doctors, home care services and hospitals to identify how patients move between these instances and how small differences can affect the health of the patients. A patient trajectory is a sequence of (possibly parallel) health care events like hospitalization, visiting the doctor, receiving public health services, getting diagnosed, taking medicine, etc. These events are connected to specific times or intervals of times in the patient's life. The patient trajectories consist of data from electronic health-care records (EHR).

The project task is to develop a system which shows a patient's medical data in a useful and understandable way. Various features should be added to give more insight to the patients about their own medical data.

ABSTRACT

As people consult the health care sector, the amount of data registered in their health records increase. The interest for insight into the medical journals is increasing. It can be strenuous for the patients to understand their own journals, and a support system is needed to make the data more manageable to grasp. Previously, the focus has been on developing systems for the clinicians and help them make clinical decisions. This master thesis focuses on the patients, providing a helpful tool to better understand their own health situation. The focus was on patients who received treatment for after having suffered a stroke. It was attempted to find the best method for visualizing the patient's health records. Possible solutions for the visualization were revealed by conducting a literature review and a workshop, and usability testing. The result was a timeline containing 1) the individual patient's health records, 2) the stroke guidelines, and 3) the typical contacts based on a group of similar patients. The stroke guidelines were incorporated into the visualization in order to give a comparable element to the patient's stroke treatment. Patients who are still receiving treatment for their stroke may draw benefits from the guidelines by seeing what will be the next stages in the treatment. Additionally, similar stroke patients were grouped together in order to find similarities in their treatments. The similarities were used to visualize the visits which were most probable of occurring in a stroke treatment. In conclusion, the project provides useful methods for handling large amounts of medical data and visualizing the data to the users.

SAMMENDRAG

I løpet av livet blir det registrert mye variert informasjon i helsejournalen til en person. Interessen for å se sin egen helsejournal har økt de siste årene. Det kan være en utfordring å forstå og tolke all informasjonen uten hjelp av et støtteapparat. Tidligere har fokuset vært på å utvikle systemer som skal hjelpe klinikere til å ta kliniske beslutninger. I denne masteroppgaven er fokuset på pasienten, og å utvikle et system som kan gi pasienten et bedre overblikk over sin egen medisinske situasjon. Fokuset har vært på pasienter som har opplevd og gjennomgått behandling for slag. Det ble forsøkt å finne den beste metoden for å visualisere pasienters helsejournal. Mulige løsninger for visualiseringen ble avdekket ved å gjennomføre et litteratursøk, idémyldring med potensielle brukere av systemet og brukertesting. Resultatet ble en tidslinje som viser 1) en pasients individuelle helsehistorikk, 2) retningslinjer for slagbehandlingen, og 3) sannsynlig behandling basert på lignende helsebesøk. Pasienter får muligheten til å sammenligne sin egen behandling med retningslinjer, og å se de neste stegene i behandlingen, noe som anses som fordelaktig. I tillegg ble lignende pasienter gruppert sammen for å finne likhetstrekk i slagbehandlingene deres. Likhetstrekkene ble brukt til å vise hvilken behandling som er mest sannsynlig å gjennomgå. Det kan konkluderes med at prosjektet gir gode metoder for å håndtere og visualisere store mengder medisinske data.

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ACRONYMS

ADL	Activities of Daily Living
EHR	Electronic Health Records
GP	General Practitioner
HELFO	Norwegian Health Economics Administration (Helseøkonomiforvaltningen)
ICT	Information and communications technology (IKT)
IPLOS	Individually based health and care service statistics (Individbasert Pleie- og OmsorgsStatistikk)
KUHR	Control of Disbursement of Health Refunds (Kontroll og Utbetaling av HelseRefusjon)
NIKT	National ICT
NST	Norwegian Center of Integrated Care and Telemedicine (Norsk senter for Samhandling og Telemedisin)
NTNU	Norwegian University of Science and Technology
PAsTAs	PAtients TrAjectories
PID	Personal IDentifier
REK	Regional Committees for medical and health research ethics (Regional komite for medisinsk og helsefaglig forskningsetikk)
RQ	Research Question
SUS	System Usability Scale

VOCABULARY

Some words have a particular meaning in this master thesis. Such words are described here.

Attribute Refers to one specific type of data found in the dataset.

Contact One specific visit with any part of the health sector.

Dataset The de-identified data used in this master thesis.

Diagnostic code Refers to one specific code, from either ICD-10 or ICPC-2.

Diagnostic code group The new groups made for this master thesis, consisting of both ICD-10 and ICPC-2 codes.

Diagnostic code system Refers to either the ICD-10 or ICPC-2 code system.

Functional level The measuring of how well a patient can attend their own needs.

Main diagnosis The diagnostic code listed as the main reason for a patient's visit with the health sector.

Source Where the data originates from, either HELFO, St. Olav's Hospital, or the municipalities.

Stroke debut The time the stroke first takes place.

Stroke indicator A label used to mark the contacts which are stroke-related.

Stroke-related A contact which has stroke as the main diagnosis.

Stroke treatment All the contacts which are related to the treatment of the stroke.

ACKNOWLEDGEMENTS

We would like to thank the members of the PAsTAs Project who allowed us to work on this project. Particularly Associate Professor Rune Sætre and Associate Professor Øystein Nytrø from NTNU whom have been the supervisors throughout the project. Staff Engineer Håkon Wågbø (former PAsTAs employee) has given valuable assistance in providing us with the necessary data from the PAsTAs project. Aslak Steinsbekk (NTNU), Professor in Behavioural sciences in medicine and Health service research, aided in the decision of the focus for the project, while Senior Researcher Gro Berntsen (NST) has provided advice on how to identify the stroke debut of the patients.

1

INTRODUCTION

The health care sector is massive and complex. Numerous departments, some private and others run by the state, make the flow of information not as streamlined as it could be. New solutions are constantly developed to make information sharing easier, trying to ensure reliable and straightforward technology. The focus so far has been on providing solutions to the clinicians and medical workers. The patients also want to collect their own information, but they do not have such helpful systems. For the average person, with few visits to the health care sector, it may be easy to obtain an overview of his/her own medical situation. However, other patients may be in frequent contact with multiple departments in the health care sector. Chronic diseases affect a majority of patients, covering 77% of the disease burden in Europe (Stene-Larsen [2010]). For chronic patients, the number of visits per year are often high, making it difficult for them to keep a clear overview of their own situation. Additionally, with comprehensive treatments and people living longer, the amount of medical data stored increases. The increase will make it more challenging for people to keep track of their own medical situations.

The focus area for this master thesis is patients who have suffered a stroke. Stroke is the third most common cause of death in Norway after coronary disease and cancer[1]. It is also a well-researched clinical condition with extensive documentation of symptoms and recommended treatments. With sturdy treatment plans, the patients can compare their treatment against the recommended plans developed by the clinicians.

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[1] https://www.ssb.no/helse/artikler-og-publikasjoner/hva-dor-man-av-i-eu-og-i-norge

1.1 MOTIVATION

Health IT systems are developed to aid the clinicians in giving the best possible treatment to their patients. Health data is being shared between different health care sectors to increase the collaboration. In 1999, patients in Norway received the right to gain access to their own medical journals, stated in §5.1 in the Patient and User Rights Law[2]. Patients would be allowed to receive copies of their medical journals, but not electronically. In the UK, a survey was carried out and revealed 73.8% of 577 patients knew they could see their own medical journals, but only 4.5% had asked to see them (Pyper et al. [2006]). The journals would need to be altered in order to be informative to a patient, because the journals are primarily written by, and for, the clinicians. The health data needs to be compressed into one health journal for each person, giving a clear overview[3]. By providing the best possible bridge between the medical data and the patient, the patient will be more confident about their own medical situation. They will also get a better understanding of what they are going through with respect to different treatments.

1.2 RESEARCH PROBLEM

The purpose of this project is to make a visual presentation of a stroke patient's health records.

GOAL: *Make a helpful tool which illustrates patient trajectories, giving the patient a clear overview of their own health situation.*

The data presented needs to be made understandable for people without a medical background. The system should be self-explanatory and the user of the system should not be dependent of any computer assistance when the system is being operated. Three research questions (RQ) were formed:

RQ1 *What is the situation for visualization of temporal data within the health care sector today?*

Looking at what has been done previously provides a solid foundation for making decisions for the new system to be developed. A literature review will be completed to give insight into existing systems, and to highlight important

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[2] https://lovdata.no/dokument/NL/lov/1999-07-02-63#KAPITTEL_6

[3] https://www.regjeringen.no/no/dokumenter/meld-st-9-20122013/id708609/

aspects related to information visualization. The developments in Norway will also be viewed. This can give insight into how this project relates to the current situation in Norway.

RQ2 *What kind of medical information is important to present to the patient?*

Various information is stored when people are in contact with the different departments of the health care sector. Receiving access to all of the information can be overwhelming for a patient, and may result in the patient becoming confused. RQ2 can be split into more specific and focused questions. For patients who are currently receiving treatment for a disease, what kind of information would be valuable for them to experience a better treatment? How much information do the patients need to see in order to be satisfied?

RQ3 *Is it useful to show (1) the individual patient trajectory, (2) the trajectories of a group of patients with the same illness as the particular patient, and (3) the clinical guidelines for the disease the patient is currently treated for, in one single visualization?*

The purpose of displaying the three components (1-3) together is to provide the patient with a better understanding of what they have been through and what they may expect to happen. The first (1) component of RQ3 to be illustrated is the patients' own trajectory. The second (2) is revealing information based upon other people who have had a similar illness as this particular patient. In the third component (3), the goal is to illustrate the clinical guidelines for the specific illness. The challenge will be to combine the three components and at the same time develop a valuable system for the patient.

After discussing the research questions and conducting the literature review, the following hypothesis is proposed.

HYPOTHESIS *People wish to (1) see an overview of their own health situation using a digital system, and (2) gradually see more details about their medical data.*

The first part of the hypothesis will be tested by doing usability testing on the developed system. The second part will be based on the result from the literature review and workshops. Finally, it will be attempted to disprove the hypothesis after analyzing the results and findings of the project.

1.3 CONTRIBUTIONS

The master thesis will propose a solution for visualizing medical data to patients. Methods for the presentation of medical data will be developed in order to give the patients valuable insight into their own medical history. These methods are grouping similar medical data together, illustrating possible future medical contacts, and comparing a patients' stroke treatment to clinical guidelines.

1.4 THESIS STRUCTURE

This project has both medical and technical aspects, both presented in Chapter 2. The methods utilized in order to accomplish the goal of this project are described next in Chapter 3. In Chapter 4, the literature review and the implemented system are presented. The results and the overall project are discussed in Chapter 5. Finally, the research questions and the hypothesis are revisited in order to determine how well they were answered after the project.

2

BACKGROUND

Visualizing patient trajectories requires knowledge about both the technological and the medical aspects. The trajectories need to be interpreted correctly in order to show the correct information to the patient. Section 2.1 introduces privacy, which is crucial when handling sensitive information. Medical data is stored in specific records, defined in Section 2.2. Section 2.3 defines relevant medical concepts for this project. This master thesis received its data from a five-year research project called PAsTAs, presented in section 2.4.

2.1 PRIVACY

Ensuring people's privacy is important when dealing with sensitive information. Sensitive information can be a person's name, telephone number, or banking information. It is common to guarantee safety by requesting a password, or a key, in order to access sensitive information. The demands to privacy and safety are increasing because of the rising amount of sensitive data being shared with the through technology (Samarati and Sweeney [1998], Pyper et al. [2006]). Powerful anonymization systems have been developed to ensure the security of sensitive information[1]. Two terms are often referred to when talking about stripping any identifiable details from the data (Berman [2002]):

- De-identified data cannot identify a person, because it is stripped of all such ID's. It is still possible to trace back to the person if necessary, using a specific key.
- Anonymous data is similar to de-identified data, but it cannot be traced back to the person it originated from. All link keys between the data and the ID's have been removed.

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[1] http://arx.deidentifier.org/

An example of de-identified data is substituting a person's name with a Personal IDentifier, *PID*. The PID can be retraced to the person's name if necessary. The circumstances where a PID is allowed to be traced back to the person requires a good reason and needs proper authorization. As mentioned, anonymous data should not make it possible to identify any single specific person in the contents. Identifiable data can be a name or a telephone number. Medical data can also be identifiable on its own, because all a person needs is the right background information about the particular person who is trying to remain anonymous. For example, an anonymous person had a heart attack one particular day, and someone knows a person who had a heart attack the same day. Consequently, it is possible to draw a conclusion and assume it is the same person, unless k-anonymity is ensured.

According to K-anonymity, each distinct attribute in the data has to be present at least *k* times (Nergiz and Clifton [2007]). *Attribute* refers to the distinctive types of data found in a particular data selection. Two methods often used to achieve k-anonymity is suppression and generalization. The method of suppression is used when an attribute is too descriptive and should be omitted from the data. An example of such an attribute is a person's name. Generalization replaces a detailed attribute value with a broader attribute group, resulting in multiple attribute values being grouped together. Generalizing peoples' age into age groups is common. The data is considered 5-anonymous when the information it portrays cannot be connected to a group of people smaller than five (Oslo Universitetssykehus [2012]). For each disease presented, there has to exist at least five people who have the same disease, or else the disease is considered too unique.

2.2 ELECTRONIC HEALTH RECORDS

An Electronic Health Record (EHR) is an assembly of registered details about a patient's health care treatment. EHRs are used for planning patient care, documenting the delivery of care and assessing the outcomes (Häyrinen et al. [2008]). All information concerning a patient is stored in the EHR, both retrospective and prospective information. The research literature done by Häyrinen et al. studied 89 papers from different countries and times. The structure of EHRs varies, but most often, they contain both unstructured free text (such as notes written by a doctor) and coded data (such as test results). The variety in structure makes it difficult to interpret and digitally utilize all of the medical data usually found in the EHRs.

2.3 MEDICAL CONCEPTS

Stroke is a chronic disease. A *chronic disease* is a disease with a long duration. It does not go away by itself, even if some form of treatment has been given (unlike a bone fracture or a flu). A stroke patient may have problems with paralysis and the ability to speak after a stroke, resulting in a long period of rehabilitation.

A *somatic health care service* refers to a person receiving treatment of the body, and not the mind (psyche). A somatic health care service could be one of the following:

- a visit to the hospital
- receiving services from the municipality (such as home care services or a nursing home)
- visit to a primary care provider (such as the general practitioner (GP) or physiotherapist)

2.3.1 *Functional Level of Patients*

Identifying how functional a patient is after they have suffered a disease is referred to as the *functional level* of a patient. The identification is done in several different ways. Some examples are The Rankin Scale[2] and IPLOS. Hospitals use the Rankin Scale to classify a patients' functional level after a stroke. It ranks the patient on a scale from the number 0 to 6, where zero is no symptoms and six is death. The municipalities in Norway are required to use a system called IPLOS, containing variables, ADL, for interpreting the functional level of a patient. IPLOS is a national registry used to describe the level of assistance a patient needs. ADL stands for Activities of Daily Living and focuses on the daily activities a person is able to perform. It includes activities such as going to the bathroom and shopping groceries. ADL has 17 different activities and each one is measured on a scale from one to four (1-4). Health personnel

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[2] https://secure.trainingcampus.net/uas/modules/trees/windex.aspx?resx=8750

measure a patient's ability to perform the activities. Depicting a patients' needs for assistance may give an indication of how functionally capable the patient is.

2.3.2 *Diagnostic Coding Systems*

Two different coding systems are used to describe the cause of a particular visit with the health care sector a patient may have: the *diagnostic code systems* ICD-10 and ICPC-2. The ICD-10 code set is the tenth version of the International statistical Classification of Diseases and related health problems. The ICPC-2 code set is the second version of International Classification of Primary Care. Differentiating between the two sets are important, because they are used in different contexts. ICD-10 codes are more detailed than ICPC-2 and is used by specialist health care services. ICPC-2 is more generalized and covers the primary health care services. For example, a person has stomach pain and consults his/her GP. This consultation will be registered and labeled with an ICPC-2 code corresponding to stomach pain. The person may end up at the hospital to receive treatment if the pain continues. This visit would be registered and labeled with an ICD-10 code corresponding to the specific problem in the abdomen the person received treatment for. One specific ICD-10 or ICPC-2 code will be referred to as a *diagnostic code*.

The IDs in both code systems consist of a letter followed by either two, three, or four numbers. The Health Directorate of Norway produced an online tool showing a structured representation of all the codes within ICD-10 and ICPC-2[3]. The highest level of granularity is shown in Figure 1. A visit with the health care sector labeled with the letter K where the diagnostic code system is not specified, can represent either the digestive system (ICD-10 code) or problems with the cardiovascular system (ICPC-2).

2.3.3 *Clinical Guidelines*

Clinical guidelines support the health care professionals in facilitating, managing, and treating a specific clinical condition (Garcia et al. [2012]). Often, the guidelines are accessible for patients as well, giving them the possibility to gain more information on how the treatment is conducted for a particular

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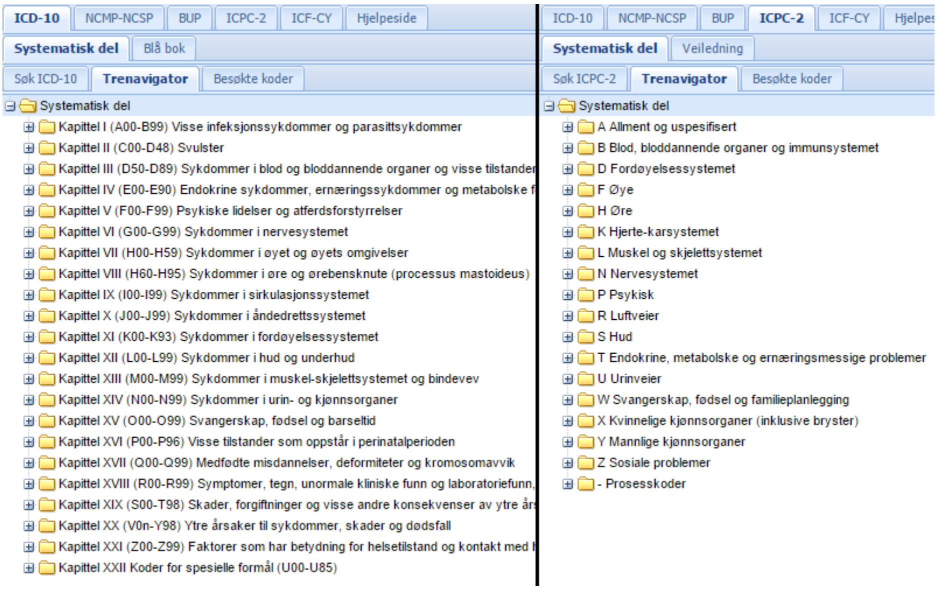
[3] https://finnkode.helsedirektoratet.no/



Systematisk del
- Kapittel I (A00-B99) Visse infeksjonssykdommer og parasittsykdommer
- Kapittel II (C00-D48) Svulster
- Kapittel III (D50-D89) Sykdommer i blod og bloddannende organer og visse tilstander
- Kapittel IV (E00-E90) Endokrine sykdommer, ernæringssykdommer og metabolske f
- Kapittel V (F00-F99) Psykiske lidelser og atferdsforstyrrelser
- Kapittel VI (G00-G99) Sykdommer i nervesystemet
- Kapittel VII (H00-H59) Sykdommer i øyet og øyets omgivelser
- Kapittel VIII (H60-H95) Sykdommer i øre og ørebensknute (processus mastoideus)
- Kapittel IX (I00-I99) Sykdommer i sirkulasjonssystemet
- Kapittel X (J00-J99) Sykdommer i åndedrettssystemet
- Kapittel XI (K00-K93) Sykdommer i fordøyelsessystemet
- Kapittel XII (L00-L99) Sykdommer i hud og underhud
- Kapittel XIII (M00-M99) Sykdommer i muskel-skjelettsystemet og bindevev
- Kapittel XIV (N00-N99) Sykdommer i urin- og kjønnsorganer
- Kapittel XV (O00-O99) Svangerskap, fødsel og barseltid
- Kapittel XVI (P00-P96) Visse tilstander som oppstår i perinatalperioden
- Kapittel XVII (Q00-Q99) Medfødte misdannelser, deformiteter og kromosomavvik
- Kapittel XVIII (R00-R99) Symptomer, tegn, unormale kliniske funn og laboratoriefunn,
- Kapittel XIX (S00-T98) Skader, forgiftninger og visse andre konsekvenser av ytre år
- Kapittel XX (V0n-Y98) Ytre årsaker til sykdommer, skader og dødsfall
- Kapittel XXI (Z00-Z99) Faktorer som har betydning for helsetilstand og kontakt med
- Kapittel XXII Koder for spesielle formål (U00-U85)

Systematisk del
- A Allment og uspesifisert
- B Blod, bloddannende organer og immunsystemet
- D Fordøyelsessystemet
- F Øye
- H Øre
- K Hjerte-karsystemet
- L Muskel og skjelettsystemet
- N Nervesystemet
- P Psykisk
- R Luftveier
- S Hud
- T Endokrine, metabolske og ernæringsmessige problemer
- U Urinveier
- W Svangerskap, fødsel og familieplanlegging
- X Kvinnelige kjønnsorganer (inklusive bryster)
- Y Mannlige kjønnsorganer
- Z Sosiale problemer
- - Prosesskoder

Figure 1: Snapshot of "FinnKode" - Helsedirektoratet

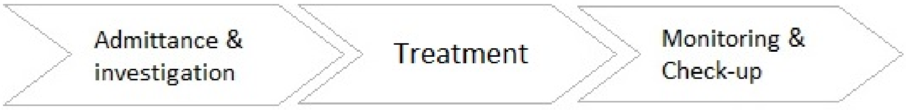


Figure 2: Overall steps of the guidelines - the University Hospital

disease. The challenge for the patients will be to understand the guidelines, since they are intended for clinicians who are acquainted with the clinical vocabulary.

The main objective with the guidelines is to show the different routes patients with a particular disease may take (Kaasa [2014]). Consequently, the guidelines need to be complex enough to include all the various patients, but at the same time to be understandable and useful for a single patient. Vice President Stein Kaasa at the University Hospital spoke about the importance of developing correct and detailed clinical care pathways at the Hemit-conference in 2014[4]. Developing the best possible guidelines is one of the three focus areas of the University Hospital. All the guidelines are to have the same structure, example shown in Figure 2.

The Norwegian Directorate of Health has published guidelines for treating and rehabilitating stroke patients (Helsedirektoratet [2010]), shown in Appendix A. The guidelines are illustrated in a flowchart, stating in what order the steps in the treatment should be executed, and consequently which sequences should be avoided. For instance, a patient should always have an examination before being admitted into the stroke ward, and not vice versa. The actual moment the stroke occurred will be referred to as the *stroke debut*. From looking at the guidelines, the different paths the patients can take become clear. Patients experience stroke differently and need various treatments.

The stroke department at St. Olav's Hospital in Trondheim developed another representation of the stroke guidelines. Here, the guidelines are presented in a timeline with lanes corresponding to various services. Procedures to be performed are placed in the lane corresponding to where the procedure takes place. Time intervals are shown over the different procedures to inform when the different procedures need to be conducted after the stroke debut. Figure 3 shows the second step in the guidelines. The treatment step starts with the

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[4] http://www.hemit.no/no/Velkommen-til-Hemit/Aktuelt/Nyhetsarkiv-2014/Programmet-til-Hemit-konferansen-2015-er-na-klart/131086/

patient being admitted into the stroke unit (”Mottak slagenhet” in Figure 3) within the first 0-12 hours after the stroke debut. Furthermore, the patient will get emergency treatment (”Akutt behandling”) and a medical evaluation (”medisinsk vurdering/utredning”) within the next 12-72 hours. The treatment step takes place at the stroke unit (”slagenhet”), and therefore only one lane is present in Figure 3. The other two steps (admittance and monitoring) in Figure 2 are built up the same way as in Figure 3. A person can receive more details by clicking on the boxes in the guidelines. Guidelines such as the stroke guidelines are accessible online[5].

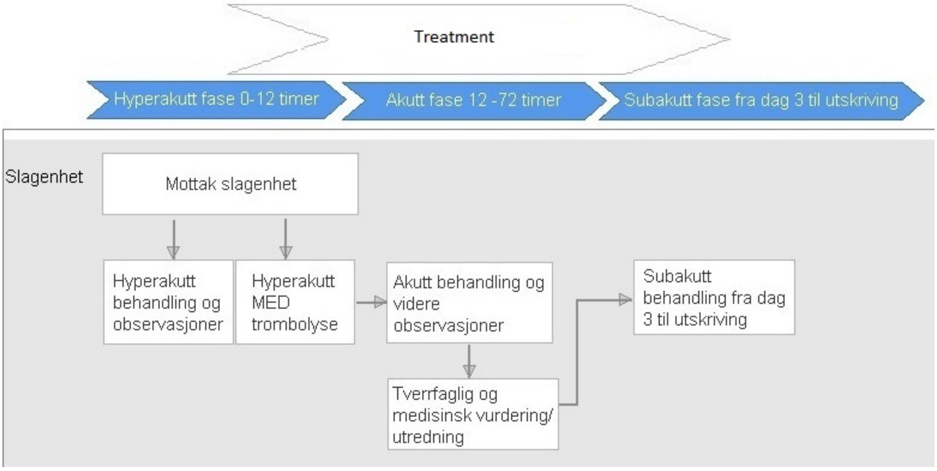

Figure 3: Second step of stroke guidelines - the University Hospital

2.4 THE PATIENTS TRAJECTORIES PROJECT

The Patients Trajectories Project (The PAsTAs Project)[6] is a collaboration between the Norwegian University of Science and Technology (NTNU) and the Norwegian Center of Integrated Care and Telemedicine (NST), with the goal to develop methods for using data from EHRs to investigate patient trajectories. The PAsTAs Project is a register-based study using data concerning so-

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[5] http://www.helse-midt.no/ftp/stolav/eqspublic/pasientforlop/docs/doc_22384/index.html

[6] http://telemed.no/pastas-pasientforloep.5219575-247952.html

matic health care utilization from a two-year period (2012 and 2013). Regional Committee for Medical and Health Research Ethics in Central Norway (REK 2011/2047) approved the study. This approval was the basis for consent to extract data from the following *sources*:

- the University Hospital in Central Norway (specialist care),
- four adjacent municipalities in Central Norway, and
- the Norwegian Health Economics Administration, HELFO[7] (primary and specialist care) with the use of their database KUHR[8].

In total, the PAsTAs project covers de-identified patient data for 180 000 people.

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[7] Norwegian Health Economics Administration

[8] Control of Disbursement of Health Refunds

3

METHODS

In this chapter, the various methods used in this project are explained. The chapter is divided into three parts: the overall process for the project (Section 3.1), methods for information gathering (Section 3.2 and Section 3.3), and methods for developing the system (Section 3.4 and Section 3.5). Section 3.1 introduces the overall process for the project, and Section 3.2 shows the strategy applied for the literature review. The workshops are presented in Section 3.3. Section 3.4 introduces the methods used to develop the system and to obtain the desired data. The final section explains the methods used for testing the system, and explains how the testing was carried out. As each section is introduced, some research questions (*RQ*), will be addressed to clarify how the sections help answer these questions.

3.1 THE PROJECT PROCESS

To complete the project as efficiently as possible, a detailed plan was needed. Various processes were discussed, and the process by Kothari was finally chosen (Kothari [2004]), seen in Figure 4. The order of the sections in the subsequent chapters follow this project process closely.

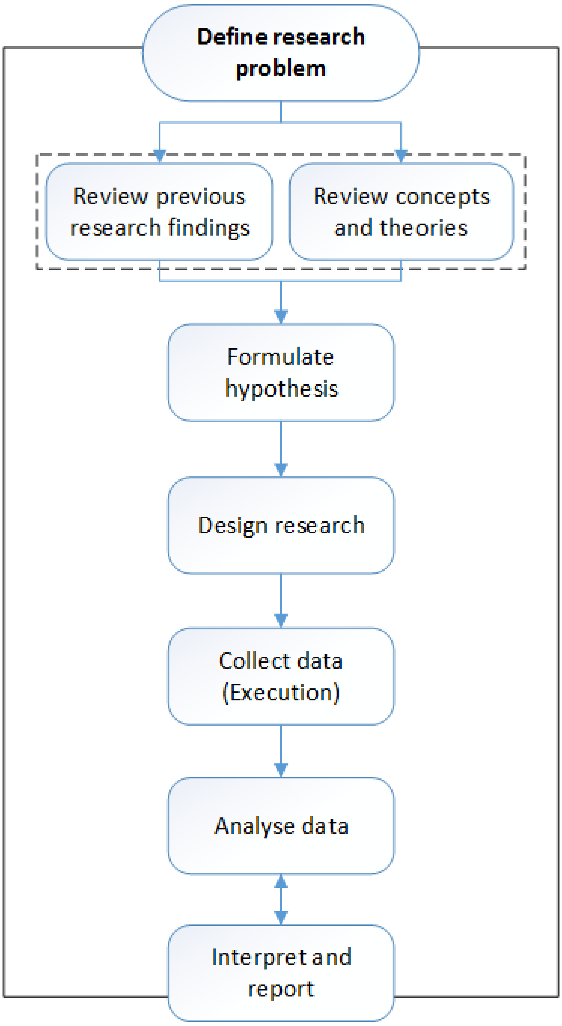
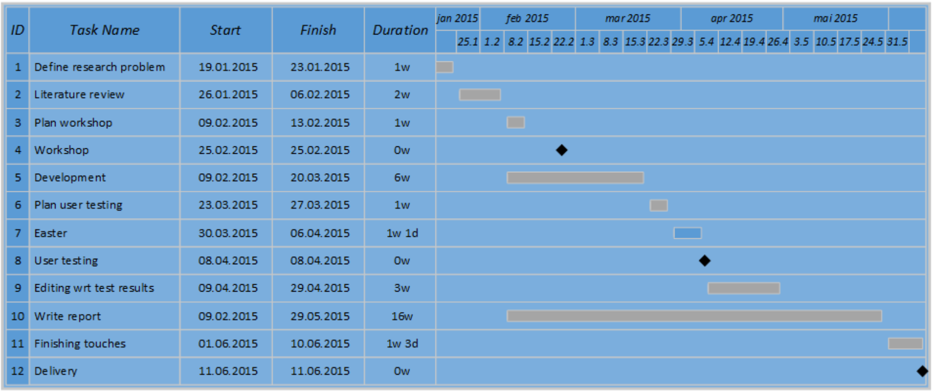


Figure 4: The project process (Kothari [2004])

The first step in Figure 4 is to define the research problem. Here, the project's supervisors were important in assisting to understand the problem at hand. The research problem was introduced in Chapter 1. Once the problem description was clearly defined, the review step could be initiated. In this step, concepts and previous research findings were studied, and the results will be shown in Section 4.1. Descriptive research, meaning research consisting of discovering



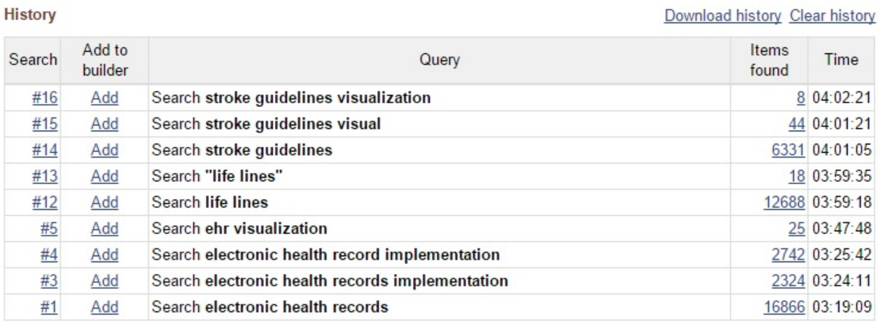
ID	Task Name	Start	Finish	Duration
1	Define research problem	19.01.2015	23.01.2015	1w
2	Literature review	26.01.2015	06.02.2015	2w
3	Plan workshop	09.02.2015	13.02.2015	1w
4	Workshop	25.02.2015	25.02.2015	0w
5	Development	09.02.2015	20.03.2015	6w
6	Plan user testing	23.03.2015	27.03.2015	1w
7	Easter	30.03.2015	06.04.2015	1w 1d
8	User testing	08.04.2015	08.04.2015	0w
9	Editing wrt test results	09.04.2015	29.04.2015	3w
10	Write report	09.02.2015	29.05.2015	16w
11	Finishing touches	01.06.2015	10.06.2015	1w 3d
12	Delivery	11.06.2015	11.06.2015	0w

Figure 5: Gantt chart for the whole master thesis

relevant surveys and fact-finding inquiries, was used in the review step. Applied research was also used, meaning to conduct research and find a solution for this project. Building upon previous research within information visualization, gives the current research problem a stronger foundation. The hypothesis was formulated based on the research results and the research questions (see Chapter 1). When the hypothesis and the research questions were ready, the design research was planned. With a clear plan for the execution, the project could be completed more efficiently and with fewer derailments. A Gantt chart was made to distribute the various project tasks throughout the time span of the project, shown in Figure 5. The execution of the project was initiated when the plan was ready. This involved the development of the system. Subsequently, the whole system was analyzed and tested to see if the results were acceptable. Finally, the research questions and the hypothesis were revisited to assess the overall execution.

3.2 LITERATURE REVIEW

RQ1 asks how the situation is today for visualizing temporal data. The question can be answered by conducting a thorough literature review. The first step was to define what keywords to search for and where to look for the relevant literature. The keywords selected were ″information visualization″ and ″visualization of electronic health records″. Several databases with useful pub-



Search	Add to builder	Query	Items found	Time
#16	Add	Search **stroke guidelines visualization**	8	04:02:21
#15	Add	Search **stroke guidelines visual**	44	04:01:21
#14	Add	Search **stroke guidelines**	6331	04:01:05
#13	Add	Search **"life lines"**	18	03:59:35
#12	Add	Search **life lines**	12688	03:59:18
#5	Add	Search **ehr visualization**	25	03:47:48
#4	Add	Search **electronic health record implementation**	2742	03:25:42
#3	Add	Search **electronic health records implementation**	2324	03:24:11
#1	Add	Search **electronic health records**	16866	03:19:09

Figure 6: Search history - PubMed

lications were used, including NTNU's own library search engine[1], PubMed[2], Web of Science[3], and Google Scholar[4]. NTNU has its own archive of previous students' master theses, and was used to discover suitable projects[5]. Figure 6 shows some of the searches done in PubMed and the number of results each search returned. After reading the abstracts of the selected literature, it was decided whether a particular publication should be chosen for a closer assessment or not. After going through all the potential literature and choosing the most relevant, a more thorough read-through was conducted. The publications consisting of value for this project were finally selected after the read-through. The chosen literature is presented in two groups: visualization of information in general and visualization of information with a focus on medical data.

3.3 THE DESIGN WORKSHOP

Input from different potential users was needed in order to develop a useful product. Conducting a workshop could give such input. The Organization for Disabled (FFO), and the User Committee[6] (UC) at the University Hospital were invited to give feedback on the visualization. The feedback would be on what

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[1] http://www.ntnu.no/ub
[2] http://www.ncbi.nlm.nih.gov/pubmed
[3] http://www.webofscience.com/
[4] http://scholar.google.no/
[5] DAIM - Digital Archive and Submissions of Master Thesis
[6] "Brukerutvalget" in Norwegian

information should be shown (in conjunction with RQ2) and how to incorporate the stroke guidelines (RQ3) into the system. UC and FFO were helpful in getting in contact with potential participants for the workshop. Appendix C shows the invitation sent out to recruit participants. The invitation consisted of a short summary of what the master thesis concerned, and what topics would be discussed at the workshop.

Using information collected in previous workshops was also a possibility. Such a workshop was conducted by the PAsTAs project in September 2013[7]. Gry Seland, who has a doctorate degree on role-play workshops, led the workshop (Seland [2010]). The purpose was to get input on how to develop a website where the patient could see their own patient trajectory, and answer questions by regarding their own trajectory. The participants were cancer patients and researchers. They were placed in separate groups and were asked to complete the same tasks. By doing this, the results from the groups could be compared, giving insight in how the two groups (patients and researchers) may think differently or similarly. The tasks given to the participants were as follows:

- Individual task, "draw your own trajectory"
- Group task, "construct a trajectory solely based on medical data"
- Group task, "expand the trajectory to make it more personal"
- Individual task, "write questions you would like to be asked based on your own trajectory"

3.4 SYSTEM DEVELOPMENT

From the literature review (Section 4.1), various information visualization techniques were discovered. Having a good interactive visualization interface can result in a better performance of the entire system (Ware [2013]). Different web technologies were assessed in order to select the most suitable technology for this system. Various requirements and suggestions for the system were discussed and possible solutions were developed and analyzed. These possible solutions could be either paper-based or computer-based. Further discussions were based upon these solutions, trying to find the best solutions for this project. In conclusion, the decision was to develop a web page. To construct

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[7] Title: "Oppsummering av deltakende design-workshop 11.09.2013 i PATH og PAsTAs-prosjektet"

the timeline, the CHAP Links Timeline[8] was used. JavaScript and HTML5 are the programming languages used in CHAP Links. NetBeans[9], an integrated development environment (IDE), was also used to develop the system.

In the following subsections, important aspects of the system are explained. The first subsection, 3.4.1, lists the steps taken to collect the data for the project. The next subsection (3.4.2) mentions the methods used for grouping contacts to make it easier to interpret the data. The term *contact* refers to one specific visit with the health care sector. Methods for grouping comparable patients are mentioned in the third subsection (3.4.3). Subsection 3.4.4 explains how a group of patients can be used to identify probable contacts occurring in a stroke treatment. One of the grouping methods from Subsection 3.4.3 is used to find the probable contacts. The final subsection (3.4.5), mentions how the stroke guidelines can enhance a patient's visualized stroke treatment.

3.4.1 *Data Selection*

Retrieving data from as many sources as possible gives the most accurate and holistic view of each patient (Bettencourt-Silva et al. [2012]). The PAsTAs project received data from three sources, each giving insight into the health care utilization within and across specialist and primary health care[10]. Figure 7 shows the stages taken to reach the final data selection for this master thesis. The dotted line illustrates the division between what was done by the PAsTAs project and what was done in this master thesis. The number of PIDs remaining at each stage is presented. A PID represents one patient in the data. The first stage is the 180 000 PIDs the PAsTAs project received. Selecting 10% of the PIDs at random was determined as a large enough base of people for the extraction of several 100 stroke patients. Out of the 18 000, the PIDs without stroke are removed. Table 1 lists the steps taken to achieve the final selection among the 1 147 PIDs. In the following sections, the steps will be further explained, and the attributes of the final data selection are presented.

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[8] http://almende.github.io/chap-links-library/
[9] https://netbeans.org/
[10] https://www.ntnu.no/wiki/display/pastas/HOME

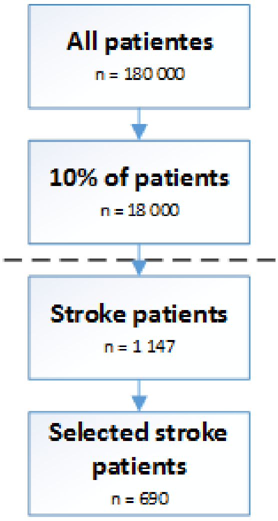

Figure 7: Stages of the data

Step	Action
0	Collecting data (n=1 147)
1	Stroke debut identification (n=690)
2	Making the data anonymous

Table 1: Steps of data extraction and alteration

Step 0: Collecting data

Out of the 18 000 PIDs, the stroke patients were identified (n=1 147). As long as a patient had at least one stroke-related contact, the patient was included. The term *stroke-related* is defined as a contact with a stroke diagnosis. A contact may consist of multiple diagnostic codes, but only the *main diagnosis* was used for this master thesis. All the stroke-related diagnostic codes are listed in Appendix D. The contacts were labeled with a *stroke indicator*, separating stroke-related contacts from not stroke-related contacts (and those without any diagnostic codes). The contacts from the municipalities did not have any diagnostic codes, making it difficult to determine the main cause for the contacts.

Some inclusion and exclusion criteria were decided by the PAsTAs project. All people aged 18 years and older before the last day in the two-year period were included. Additionally, a visit to a somatic health care service must be present in the period. Patients with serious psychiatric or psychological diagnoses were excluded. Furthermore, patients without stroke were excluded from this master thesis.

Step 1: Stroke debut identification

The stroke debut was needed to make it possible to detect similarities and differences, between multiple stroke treatments or between a stroke treatment and the stroke guidelines. A patient's *stroke treatment* consists of all stroke-related contacts and all contacts from the municipalities taking place after the stroke debut within a certain period. The municipality-contacts were included, because they are often relevant for the rehabilitation steps taking place after the patient returns home. The debut is not marked with any extra identification, and could be difficult to pinpoint. The first stroke-related contact a patient has might not be the stroke debut, because it could have taken place outside of the two-year period. It was assumed that a person who had a six-month period with no stroke-related contacts was equivalent to a person not currently receiving treatment for a stroke. All PIDs with a stroke-related contact within the first six months were therefore excluded, removing 457 PIDs with an uncertain stroke debut. For PIDs with a six-month period without any stroke-related contacts, it was safe to assume the first stroke-related contact presented the stroke debut. The term *dataset* will refer to the data of the 690 remaining patients.

Step 2: Anonymizing the data

The dataset received from the PAsTAs project had been de-identified by replacing the identifiable attributes with secret and untraceable PIDs. The dates had also been altered. It does not matter how time are portrayed as long as the temporal relations between the contacts of each patient are intact. The relations between contacts can still be recognizable by using fictive dates or only showing the number of days between each contact. For this dataset, fictive dates were used.

K-anonymity was also used (Nergiz and Clifton [2007]). The goal was to have 5-anonymity when visualizing the data to the users. In order to achieve this goal, the diagnostic codes were shortened to consist of only the first letter and the first number of the original diagnostic codes. The number of PIDs present for each code are shown in Table 19 in Appendix E and shows that 5-anonymity was not yet reached. The solution was to visualize the diagnostic codes based solely on the first letter, resulting in large enough groups of PIDs (see Appendix E).

The first number in the diagnostic codes was still valuable to label the contacts correctly. For instance, ICD-10 codes starting with the letter D could be either tumors ("Svulster" in Figure 1, consisting of the codes D00-D48) or a disease in the blood or blood-forming organs ("Sykdommer i blod og bloddannende organer", consisting of the codes D50-D89). Misinterpreting the codes could falsely portray a patients' health, causing confusion when presenting the data to the patient it concerns. Table 21 in Appendix E shows how the diagnostic codes were divided to still comply with the 5-anonymity requirement. The final diagnostic groups (with 5-anonymity) resemble the hierarchy of Figure 1 in Section 2.3.2.

The final data selection

The final attributes in the dataset are listed in Table 2. The dataset consisted only of the necessary attributes needed in order to complete the project. Some attribute names were altered to be more readable than the names originally used in the data. Some attribute data was altered by the PAsTAs project in the previous steps (such as *Date*), while other attributes remained unchanged (such as *PID*). Two new attributes were also added, the *Stroke Indicator* and *Diagnostic Code System*.

Source	**Attributes**
HELFO (KUHR)	PID, Date, Service Name, Stroke Indicator, Diagnostic Code, Diagnostic Code System
St. Olav's Hospital	PID, Display Name, Start Date, End Date, Stroke Indicator, Diagnostic Code, Age Group
Municipalities	PID, Service Name, Start Date, End Date

Table 2: Final attributes in dataset

The *PID* attribute makes it possible to connect contacts from different sources for all patients. The *Service Name* states what service a specific contact is connected to (for instance the GP or physical therapy). The *Diagnostic Code* is the abbreviated diagnostic code consisting of a letter and one number, while the *Diagnostic Code System* tells if the current diagnostic code belongs to ICD-10 or ICPC-2. All diagnostic codes in the dataset were placed in the same column, not taking into account what kind of diagnostic code they were. Section 2.3.2 explains the importance of detecting what kind diagnostic code system the various diagnostic codes originate from.

St. Olav's Hospital uses some of the same attributes as HELFO. *Display Name* tells what kind of service the contact is concerned, such as a bedpost or surgery. *Start Date* and *End Date* states the time interval a contact took place. The *Age Group* attribute showed what age interval a patient belonged to, listed in Table 3. There was no *Diagnostic Code System* attribute, because all the diagnostic codes in the St. Olav's files originate from the ICD-10 code system.

Age group	**Age interval**
5	17 - 19 years
6	20 - 44 years
7	45 - 66 years
8	67 - 79 years
9	80 - 89 years
10	90 - years

Table 3: Age intervals in the dataset

The municipality data had the least amount of attributes. This was mainly because they had no diagnostic codes and consequently were not in any diagnostic groups.

3.4.2 *Grouping of Similar Contacts*

Chronic diseases, such as stroke, result in multiple visits to the health care sector. Having an illness with a slow progression and a long duration, the number of contacts (such as visiting the GP and physical therapy) may be hard to keep track of. Portraying contacts in a timeline could help put the contacts in perspective, but remembering the purpose of each visit may still be difficult. To make the timeline more useful, the contacts could be grouped so the patient could see patterns and recognize the contacts in the timeline, as shown in Figure 8. In Figure 8A, contacts are being divided into groups and put into

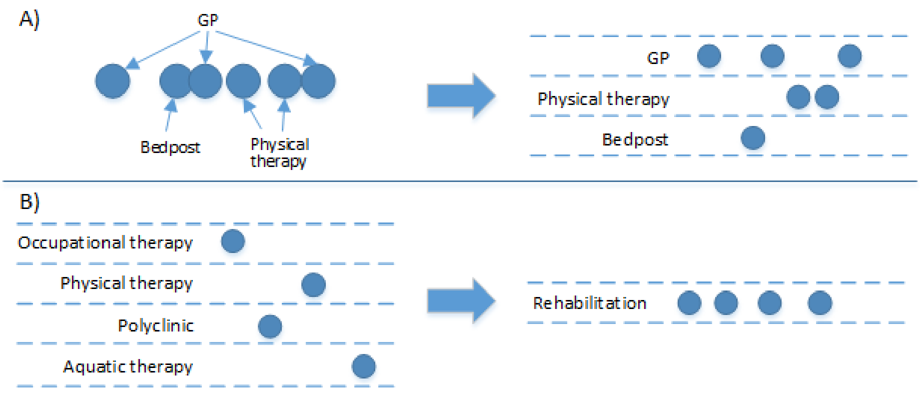

Figure 8: Two options for grouping contacts

individual lanes based on these groups. The contact types became easier to distinguish from each other, being valuable when presenting numerous contacts to a patient. Another form of grouping is portrayed in Figure 8B where similar, specialized contacts are merged into a group with a generalized theme.

The thematic grouping of the contacts had two possibilities: services and diagnoses. Contacts were grouped by the type of service the contact concerned, such as visiting the GP or being placed in a bedpost at the hospital. The information needed to group the contacts was derived from the following attributes in the dataset: *Service Name* from KUHR and the municipalities and *Display Name* from the University Hospital. There was a total of 271 different labels used in the dataset. The labels were grouped together by analyzing all labels and deciding which relates to one another, as shown in Figure 8B. The 271 specific labels were condensed into 19 generalized groups. Table 4 lists the 19 generalized groups and the number of specific services present in each. Additionally, the number of contacts connected to each service group is listed.

The second thematic grouping of contacts is the diagnostic grouping. Using the ICD-10 and ICPC-2 code systems, found in the data from KUHR and the University Hospital as the *Diagnostic Code* attribute, diagnostic grouping could be conducted. The diagnostic code names used in the two sources often resemble each other, as seen in Section 2.3.2, Figure 1. For instance, letter L in ICD-10 and S in ICPC-2 both concern the skin, and can therefore be grouped together. The challenge with the diagnostic codes was that they were placed

Service group	**Services**	**Contacts**
Akutten	1	21
Bistand	13	1 189
Bolig	9	70
Dagpost	4	106
Dialyse	3	778
Diverse	37	1 198
Elektiv	1	19
Fastlege	1	21 968
Kirurgi	23	350
Legevakt	2	2 205
Opphold	31	1 200
Ortopedi	5	104
Overvåkning	4	79
Prøver	2	233
Rehabilitering	83	14 927
Sengepost	41	2 149
Spesialist	7	1 528
Stråleterapi	1	2
Tannhelse	3	200
Total	**271**	**48 326**

Table 4: Service groups statistics

in the same attribute in the dataset. The diagnostic codes needed to be separated into ICD-10 and ICPC-2 groups before they could be merged together. Section 3.4.1 mentioned what diagnostic codes was used in the various sources. The University Hospital uses ICD-10, HELFO uses both, and the municipalities does not use diagnostic codes. To separate the diagnostic codes in HELFO, the *Service Name* attribute indicates if the contact belongs to primary (ICPC-2) or specialist care (ICD-10). The new group consisting of skin-related codes (L in ICD-10 and S in ICPC-2) was called a *diagnostic code **group***. Table 5 lists up the new groups when the similar ICD-10 and ICPC-2 codes were paired. The diagnostic code systems are not the same and should not be confused with each other. The *ID* label represents the new group. It is nexessary to differentiate between *Diagnostic **group** A* and *Diagnostic **code** A*. Diagnostic code A would either reference to the ICD-10 or the ICPC-2 code A, while the diagnostic group A references to the group presented in Table 5 ("Allment of uspesifisert"). The corresponding total number of PIDs in each diagnostic group is also shown. Every group can be shown in the timeline, because they meet the 5-anonymous requirement.

3.4.3 *Grouping of Comparable Patients*

RQ3 mentioned grouping patients together who have had the same illness, such as stroke. Patients' stroke treatments are seldom identical, as seen in the two guidelines introduced in Section 2.3.3. Some people may have experienced a light stroke with no rehabilitation. Other patients may have been affected more seriously and need assistance with everyday tasks afterwards. The patients may perceive their own treatment in a new way, when grouped together. They learn how their stroke treatment was similar to other stroke-patients, and can therefore assume their treatment was a regular one. On the other hand, they may also become aware of how rare their treatment really was. Possible criteria for grouping patients were:

- age
- previous medical history
- functional level

As people get older, their body becomes weaker. A person who is 40 years would normally have an easier time recovering from a stroke than a person who is 70 years. Comparing people who are around the same age could there-

ID	Group name	Diagnostic codes	Total PIDs
A	Allment og uspesifisert	W & Y (ICD-10) A (ICPC-2)	914
B	Blod og immunforsvaret	D5-D8 (ICD-10) B (ICPC-2)	121
C	Fordøyelsessystemet	K (ICD-10) D (ICPC-2)	536
D	Øyet	H0-H5 (ICD-10) F (ICPC-2)	435
E	Øret	H6-H8 (ICD-10) H (ICPC-2)	225
F	Sirkulasjonssystemet	I (ICD-10) K (ICPC-2)	1 147
G	Muskel og skjelett	M (ICD-10) L (ICPC-2)	688
H	Nervesystemet	G (ICD-10) N (ICPC-2)	536
J	Åndedrettssystemet	J (ICD-10) R (ICPC-2)	546
K	Hud og underhud	L (ICD-10) S (ICPC-2)	438
L	Ernæringsmessige problemer	E (ICD-10) T (ICPC-2)	367
M	Urin- og kjønnsorganer	N & X (ICD-10) U (ICPC-2)	611
O	Svangerskap, fødsel og barseltid	O (ICD-10) W (ICPC-2)	23
Q	Medfødte misdannelser	Q (ICD-10)	13
R	Skader, ytre årsaker	S & T (ICD-10)	265
S	Svulster	C & D0-D4 (ICD-10)	226
T	Unormale funn	R (ICD-10)	482
U	Infeksjonssykdommer	A & B (ICD-10)	80

Table 5: New diagnostic groups

fore give more meaning rather than comparing the 40-year-old with the 70-year-old. The 70-year-old could perceive his/her treatment as a common treatment if it was compared to other 70-year-olds. The attribute *Age Group* makes it possible to group patients by their age and study their stroke treatments accordingly.

Looking at a person's medical history prior to the stroke can also be used to differentiate between people. A person with little association with the health care sector, who suddenly suffers a stroke, may have a better starting point when receiving treatment. Similarly, a person with continuous contact with the health care sector for multiple problems may need a longer and more extensive treatment plan if they suffer a stroke.

The third possible criteria for grouping was by functional level. There are different scales for measuring the functional level. The Rankin Scale and ADL were introduced in Section 2.3.1 and could be used for such purposes as identifying similar patients. By such grouping, patients in a particular group may receive similar services throughout their treatment

3.4.4 *Discovering Probable Contacts*

Some contacts appeared more frequently in the dataset than others, and thus were looked upon as the most probable contacts in the stroke treatment. The probable contacts could be used in various ways. One way was by showing a stroke patient, who was not yet done with his/her treatment, what similar patients went through in their treatments. In this context, the probable contacts illustrates possible future contacts for the particular patient. Probable contacts could also be used retrospectively. Patients who were finished with their stroke treatment could look back on their treatment and see how their contacts matched the probable contacts within the similar group of people.

Grouping similar patients together, as explained in the previous section, was necessary when finding the probable contacts. Grouping patients by their age was the method chosen for identifying the probable contacts. The age groups found in the dataset, see Table 3, were used to cluster PIDs together. The age groups contained varying number of patients, and three of the age groups were considerably smaller than the others were. A small group of patients would not be a good representation of the age group as a whole. Those groups were therefore merged together with their neighboring groups. Table 6 shows the age groups within their respective age class.

Age class	Age group	PIDs	Total PIDs
1	5 6 7	1 26 182	209
2	8	224	224
3	9 10	214 43	257

Table 6: The new age classes

Using the same logic as with the grouping of patients, contacts were grouped together. Two approaches could be used, as explained in Section 3.4.2. Using diagnostic codes would be an undesirable choice, since not all contacts contain a diagnostic code. Therefore, the service-grouping approach was applied. The 19 generalized service groups (see Table 4) were chosen to achieve a considerable size on the contact groups. In the remainder of this section, the method for discovering probable contacts will be explained systematically, followed by a mathematical explanation.

Step	Action
1	Aligning patients by stroke debut
2	Finding the average number of contacts on each day
3	Calculating the uniform average number of contacts on each day
4	Finding the average number of contacts, all days combined
5	Selecting the most probable contacts

Table 7: Steps for finding probable contacts

The probable contacts were found by following a list of steps (see Table 7). Step 1 aligned the patients' contacts by the stroke debut, as shown in Figure 9. By aligning the patients, the position of a specific contact for one patient could be compared to similar contacts of other patients.

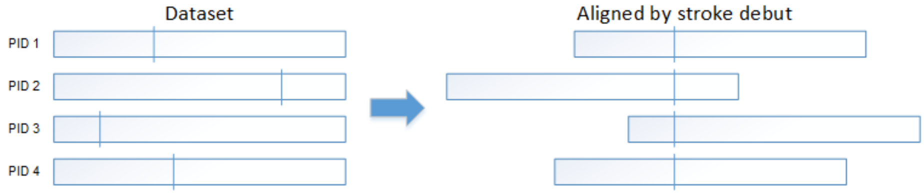

Figure 9: Alignment of PIDs

The next step was to find the daily average number of contacts for a specific service group for each PID. To find the daily average, two variables were needed: (1) the number of contacts in the specific service group on the specific day, and (2) the number of patients in the specific age class present in the dataset on the specific day. The first variable was found by tallying up the number of contacts taking place on each day for the respective service group belonging to the PIDs in the appropriate age classes. On the first day after the stroke debut, the second variable (2) was the same as the number of PIDs in the age class: either 209, 224, or 257 PIDs. Gradually the number of PIDs were reduced because the PIDs reached the end of their two-year period at different times, as seen in Figure 9. The daily averages (achieved by dividing the two variables with each other) could vary a lot from day to day.

To make a uniform average, step 3 in Table 7 found an average using a larger time interval instead of one day. The interval chosen was 14 days, resulting in a daily average neither too arbitrary nor too similar to the neighboring days. Figure 10 illustrates the benefit of using an interval average instead of a daily average. Time point 30 in Figure 10 would be perceived as the most probable day if the daily averages (blue line) were used. However, it is during the time points 12 to 20 that the interval average (orange line) keeps a high score and should be perceived as the most probable time for a contact to occur. The interval average gives a more robust average with smoother peaks in the graph. In this figure, the intervals are calculated by the previous seven days. The uniform average was calculated by summarizing the daily averages of the previous 14 days and dividing it by the interval of 14 days.

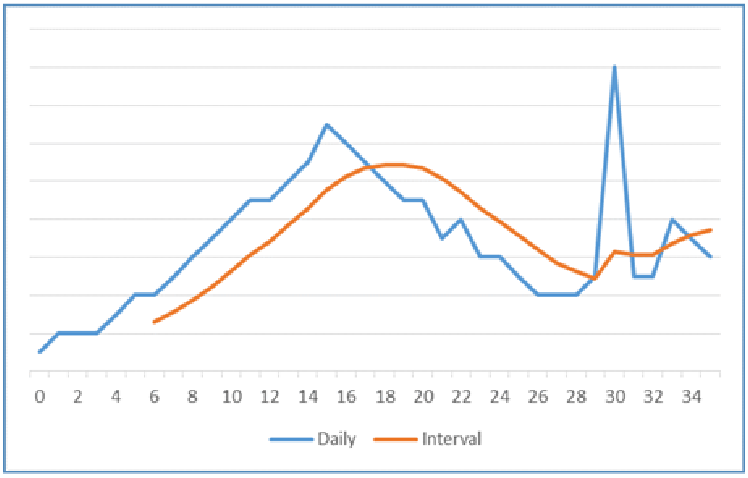

Figure 10: Illustration of daily average and interval average

Step 4 aggregates all uniform averages for a specific age class and service group, to find the average number of contacts the group patients receive for a specific service.

The last step selected the most probable contacts for a specific service group. These were the contacts with the highest uniform averages found in step 3. The number of contacts selected from each service was depended on the average found in step 4. The average was rounded to the nearest natural number, if it was rounded to zero, the specific service group did not have any probable contacts and would not be visualized.

Mathematical formulae for finding probable contacts

The method above is explained using mathematical formulae. Aligning the contacts (Step 1 of Table 7) was completed prior to what is explained in the formulae. Table 8 contains a description of all identifiers, constants, variables and functions used.

Equation 1 finds the daily average number of contacts in service group A per PID in age class B, on day C:

$$U_{A,B,C} = \frac{x_{A,C}}{y_{B,C}} \tag{1}$$

Type	Value	Description
Identifiers	A	Service group
	B	Age class
	C	The day after the stroke debut
Constants	K	Number of days for making a less incidental average (=14)
	L	The last day in the dataset (=730)
Variables	$x_{A,C}$	Number of contacts in service group A on day C
	$y_{B,C}$	Number of patients in age class B on day C
	i, j, k	Iterating indexes
Functions	$Max(n, T)$	Mulitiset with the n largest numbers in multiset T

Table 8: Description for mathematical formulae

Equation 2 finds the uniform average number of contacts in service group A per PID in age class B, on day C:

$$V_{A,B,C} = \frac{\sum_{i=C-K}^{C} U_{A,B,i}}{K} \tag{2}$$

Equation 3 finds the average number of contacts in service group A per PID in age class B:

$$W_{A,B} = \sum_{j=0}^{L} V_{A,B,j} \tag{3}$$

Equation 4 finds the multiset of the average number of contacts in service group A per PID in age class B:

$$S_{A,B} = \{V_{A,B,k} | 0 < k < L\} \tag{4}$$

Equation 5 finds the probable contacts in service group A for PIDs in age class B:

$$P_{A,B} = Max(W_{A,B}, S_{A,B}) \tag{5}$$

3.4.5 *Stroke Guidelines*

The benefits of incorporating the stroke guidelines into a patient's EHR has been mentioned in previous studies (Garcia et al. [2012]). RQ2 asked what kind of information patients would like to see visualized. One possibility was to show what is going to happen in the near future. Seeing what is coming can help patients feel more empowered, with fewer surprises throughout their treatment. Guidelines, or any other kind of treatment plan, could be used to inform patients of what may happen.

After identifying the patients' stroke treatments, they were compared to the two stroke guidelines shown in Section 2.3.3. The guidelines from the University Hospital were chosen to be used as a comparison because of their structure, shown in Figure 3. In order to compare the guidelines to a patient's stroke treatment, similar points were we needed to be identified in both. Appendix B shows the three steps of the guidelines. There were few matches between the patients' stroke treatment and the guidelines. The guidelines consisted of more detailed steps than what the patients' contacts presented. Multiple steps from the guidelines were merged into single contacts in the patients' stroke treatments. The *admittance & investigation* step in the guidelines were found in the stroke treatments as visits to a GP or the emergency room. A contact concerning a bedpost at the stroke ward at the hospital for six day would represent the whole *treatment* step in the guidelines. The last step, *monitoring & check-up* was linked to all the rehabilitation contacts found in each PIDs' trajectory after the stroke debut.

3.5 TESTING THE SYSTEM

The testing of the system was done by A/B testing and completing a System Usability Scale (SUS) survey. The criteria for the testers was to be between the ages of 20 and 85. The reason for the large range is that it gives the possibility to get feedback about the system from people with different backgrounds.

A/B testing is a test where versions of the system are being compared to see which works better. The comparison was done by having two groups of testers test one version each. Both groups were given the same tasks, making it possible to compare the results. One version would be considered the most successful version if the corresponding group of testers were able to complete the tasks considerably faster than the other group. The SUS survey is a survey the tester conducted after exploring the system[11]. The tester is given tasks to complete in order to understand all the features. After exploring the system, the tester rates the system with regards to ten different statements. A final score was

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[11] http://www.usability.gov/how-to-and-tools/methods/system-usability-scale.html

calculated based on the scores given by the testers. The score would indicate how usable the system was.

The testing of the system corresponds to the first part of the hypothesis, stating people wish to view their medical data in a digital system. One important aspect of testing the system was to detect how useful the testers thought the system was. Before each test started, the tester was asked to fill out some personal information. The information consisted of their age, gender, profession, and computational skills. The goal was to have a similar group of testers for both versions in the A/B test. The information was used to decide which version of the system a tester would get in order to keep the test groups homogeneous. The systems usability was tested by comparing the system to the testers' own methods for keeping track of their medical situation. In order to make the comparison, the tester was first asked some questions based on their own experiences, shown in Table 9.

#	**Questions for the tester**
1	When did you last visit your GP?
2	Do you remember the number of illnesses you have had in the last year?
3	How many times have you visited your GP the last three months?

Table 9: Test questions

After the testers had answered the questions above, they got access to the system and were asked to interact with it by completing some tasks. The tasks are shown in Table 10 and are similar to the questions in Table 9, which the tester just answered about themselves. The comparison will reveal if they feel the system makes it easier to answer the questions or not. The data shown in the timeline for the test is anonymous data and each tester will be shown the same data.

#	Tasks to be carried out
1	Find the date for the last GP-visit.
2	Find the illnesses the person had during the last year.
3	Find the number of GP-visits in January - March 2011.
4	Find the number of contacts related to the diagnosis muscle and skeletal system.
5	Find the number of contacts connected to the stroke treatment.
6	Find additional information about the stroke treatment.

Table 10: Tasks for the usability testing

During the testing, the testers were asked to speak aloud and explain their trail of thoughts and what actions they performed. Less interruption from the observer was preferred. Finally, the testers were asked to fill out the SUS survey (Appendix F) when they finished.

Method for Evaluating the Results of the A/B Test

A Student's t-test was used to test which version of the system was best (Haynes [2013]). The test was used to determine if it was a significant difference between the average results from the two version. The method followed the steps shown in Table 11.

Step	Task
1	Proposing a null hypothesis.
2	Finding t-threshold value from the t-distribution table.
3	Calculating the test statistic.
4	Comparing the t-threshold against the t-statistic.

Table 11: Steps for determining test results

First, a hypothesis was proposed: $H_0 : \mu 1 = \mu 2$ (the averages are equal). If the hypothesis could be discarded, the differences between the versions were statistically significant, and it could be assumed that one system was better than the other. Second, the t-threshold was found. To find the t-threshold, the degrees of freedom and the confidence level were needed. The degrees of freedom are the size of the sample of data minus 2, and the confidence level was set to 95%. A confidence level of 95% means there was a 5% chance of the evaluation being wrong. The third step calculated the test statistic using Equation 6 and 7. Equation 6 found the t-statistic, and Equation 7 calculated the pooled variance. The final step was to compare the test statistic with the t-threshold. The hypothesis would be discarded if the statistic was greater than the threshold. Otherwise, the hypothesis was proved, which in this case would mean one version of the system was not better than the other.

$$t = \frac{\mu_1 - \mu_2}{s_p^2 \sqrt{\frac{1}{\mu_1} + \frac{1}{\mu_2}}} \tag{6}$$

$$s_p^2 = \frac{(n_1 - 1)s_1^2 + (n_2 - 1)s_2^2}{n_1 + n_2 - 2} \tag{7}$$

4

RESULTS

In this Chapter, the results of the project are presented. Section 4.1 states the findings of the literature review, focusing on Research Question 1 (RQ1). A design workshop was conducted, and the results are shown in Section 4.2. Chapter 4.3 describes how the various features were visualized in the final system, focusing on both RQ2 and RQ3. The last section list the test results.

4.1 LITERATURE REVIEW RESULTS

The utilization of the EHRs has long been apparent for clinicians and researchers. The usefulness for patients is also becoming more clear (Pyper et al. [2006]). Pyper et al. conducted a survey where they summarized some benefits of patients seeing their own health records. It could be easier for patients to talk to their doctors if they had a better understanding of their own health. The patients could also make decisions more easily for themselves after discussing their EHRs with their doctor. In order to enhance the benefits, it is researched how to visualize the health records with the focus on making the best system for the patients. First, some techniques are mentioned for how to visualize information. Secondly, the visualization techniques focus on health records in particular.

4.1.1 *Visualization of Information*

Computers are of tremendous assistance when processing large amounts of data, but not as helpful at pattern recognition. For humans, it is the other way around. Being aware of the advantages the computer and the humans bring, can result in the most optimal solution for visualizing information.

Shneiderman proposed the Visual Information Seeking Mantra for designing user faces (Shneiderman [1996]). The mantra stated how the visualization of data should be built up, "Overview first, zoom and filter, then details-on-demand".

- **Overview** over the entire collection
- **Zoom** in on items of interest
- **Filter** out uninteresting parts
- **Details-on-demand**: select item/group and get details when needed
- **Relate**: view relationships among items
- **History**: support undo, replay and progressive refinement
- **Extract** sub-collections and the query parameters

According to the mantra, users should first be met with an overview of the system. Then, the user should be able to use features in the system to get more detailed information. Furthermore, the user should have the opportunity to filter out what they decide is of no interest. With only items of interest showing, it should be possible to get details about specific items when desired. The feature relate stated the user is to be presented with the relationships found among the items in the visualization. The next feature was called history, meaning the user could undo any filtering that was executed. The last feature in the Mantra was extraction. Letting the user extract sub-collections of the complete collection and query further on the extraction could give the user access to more knowledge.

The information overload problem can appear when dealing with large amounts of data (Keim et al. [2008]). This problem means getting lost in the data, and consequently the data looses its purpose. Keim et al. adjusted Shneiderman's Visual Information Seeking Mantra changed the focus from merely visualization to visual analytics: "Analyze first, Show the important, Zoom, Filter and analyze further, Details-on-demand". According to Keim et al., "visual analytics combines automated analysis techniques with interactive visualizations for an effective understanding, reasoning and decision making on the basis of large and complex data sets". Previous work within information visualization has focused on how to show the data and creating interaction techniques. Visual analytics focus more on how the user interactions can be turned into new intelligence and knowledge.

Another aspect was studying the characteristics of the data. The characteristics affect the choice of representation method (Aigner et al. [2008]). Time-oriented data, also known as temporal data, is related to time and therefore needs to be handled differently than regular data. Aigner et al. listed up the different methods for visualizing time-oriented data based on the different characteristics the data may have. Three distinctions were listed, given as:

- Linear versus cyclic time - data has a starting point and elements from past to future, versus data following a cycle (for example the seasons).
- Time points versus time intervals - no duration versus an interval-scaled time domain.
- Ordered versus branching time - chronological versus alternative scenarios.

Being aware of these distinctions can help in choosing the right method for visualizing a particular set of temporal data. It is also important to keep in mind how the data should be analyzed, for example as a cluster, and the choice of analytical methods and visualization methods depending on the user's tasks and needs.

Important topics were mentioned in the literature above. Understanding the data at hand is essential in order to be able to develop the proper illustration for it. In addition, focusing on how the user is to interact with the system, could determine how useful the system becomes.

4.1.2 *EHR Visualization*

The usefulness of computer systems within the health care sector are well known, but the systems used today are still not optimal. One challenge was making all available knowledge (such as patient records, guidelines and protocols) machine-interpretable. There are insufficient tools to promote a rapid adoption of the best practices (Panzarasa et al. [2002]). Panzarasa et al. proposed the development of a Knowledge Management System, which could deliver high quality care to different health care organizations. Panzarasa et al. focused on the stroke rehabilitation process, and developed a taxonomy of roles to show dependencies and made it machine-readable. The challenge of exceptions became clear, and the importance to be able to handle them. Here, an exception was any deviation from the ideal health care process. Patients experience illnesses differently and the treatments must be altered to satisfy their needs, causing deviations to arise.

Another system developed to make it possible to explore and analyze patient histories, was the one developed in 2006 (Nordbø [2006]). The prototype was made for researchers and clinicians to gain new knowledge and discover new hypotheses through analyzing multiple patient histories.

The challenge with EHRs was the large number of formats used to store them. Everything from databases to hard copies are being used (An et al. [2008]). The EHRs should all follow the same format and be visualized together in the same system. The clinicians could get more support to make accurate clinical diagnoses and take preventive measures for a patient, when having only one system. The many medical data standards existing today, cause the data to have different data structures, and cannot be used optimally (Kopanitsa et al. [2013]). Not only decision-making was made difficult, but also sharing the data is troublesome between various medical departments and -units. Ethical and legal implications also increased as medical data was shared, and put more demands on the technical systems. Another challenge with EHRs was the complexity of the systems using the data. A solution could be to develop a new system based on the visualization of a previous well-known system (Plaisant et al. [2008]). This resulted in not having to explain the new system to the users who were already familiar with the previous system, in this case it was Microsoft Amalga.

Often, the effort of registering data in the EHRs outweigh the amount of knowledge actually gained from the EHRs (Rind et al. [2010]). As long as the effort was larger than the pay-off, the motivation to use more time to register all information in the EHRs would be low. To enhance the motivation, the EHRs should be more useful by mixing information visualization and scientific visualization. The information part can be the mapping of large amounts of data to give meaningful information quickly. The scientific part was the EHR consisting of real objects with spatial dimensions. Rind et al. reviewed 14 such visualizing systems and stated both advantages and challenges with each. The systems helped clinicians gain new clinical knowledge by being able to ask the system questions. The clinicians would receive relevant patient data according to the parameters specified in the questions. The user would also be able to choose to see more or less information about the desired data. The systems chosen for the study fulfilled the following criteria:

- The EHR consists of entire patient histories
- The information visualization deals with discrete non-spatial data
- The application is interactive with the user
- The system focuses on patient care, clinical research and quality control

Another project focusing on improving the decision-making process for clinicians was the RAVEL project (Thiessard et al. [2012]). The large amounts of heterogeneous data in the EHRs could lead to information overflow and make it difficult to derive any knowledge. The aim was to develop a tool to aid in locating elements in an EHR. Shahar [2013] also talked about how to aid in the process of interpreting and analyzing the time-stamped clinical data. The use of a mediator was proposed in order to be able to turn the raw data into more applicable, meaningful concepts. The systems mentioned by Shahar handled both assessing multiple patients and focusing on one single patient. The systems concentrated on monitoring, visualizing, and exploring the data, resulting in good feedback in the user tests performed.

The common denominator for the articles mentioned above, is the focus on developing a tool to help the clinicians and researchers analyze and interpret EHRs. None of them addressed the needs of the patients, and how to help the patients understand their own medical history. The different focus of users is what distinguishes this master thesis from the previous work within the field of visualizing medical data. Many important aspects were mentioned, which will still be important when developing a tool for the patient instead of the clinician.

A different kind of system was developed in 2014 (Wågbø [2014]). The system illustrated medical data for the patients, and not the clinicians. It was investigated whether the same techniques could be used on EHR visualization for clinicians and patients. Additionally, it was discussed if patients would benefit from seeing their health records online. Wågbø concluded with saying the patients benefited from seeing their own health records. Additionally, the patients seemed to want ″unrestricted insight″ into their own medical data.

4.1.3 *Current Status in Norway*

The National ICT in Norway, NIKT[1], is responsible for projects related to ICT and the specialized health care services. A pilot project was recently launched with the goal to map the needs of the people if they were to get access to digital services. The question was if the people would get a better connection to the specialized health care services (Nasjonal IKT [2015]). The name of the project was DIS, Digital services In the Specialized health care services for the citizens of Norway. The starting point was to focus on the needs and expectations of patients and users in order to get the most accurate decisions and initiatives. The project resulted in the decision to give citizens one portal[2] to health services, both primary and specialized health services. Gathering all services in one location could make it easier for people to know where to go when they need medical information. According to a survey conducted by Difi[3], six out of ten people in Norway would like to have electronic communication with their GP and have online access to their own patient trajectory (Lassen [2011]).

There is much focus on creating a common domain in Norway, where people could discuss how the health care sector is doing and how it should be digitalised. EHiN[4], the national conference concerning electronic health in Norway, is hosted annually and discusses important medicaltopics. Similar conferences are HelsIT[5] and the HEMIT-conference among others, which are conducted in different contexts such as a being hosted by a university or within a geographical area in Norway. By having gatherings, knowledge is being shared. It is clear that the actors involved are working towards the same goal: enhancing the health services available for the citizens of Norway through technology.

The cancer ward at the St. Olavs Hospital in Trondheim was part of a pilot study with the development of a system called Electronic Standardized Patient trajectories, eSP (Fremstad [2014]). Standardized patient trajectories show how various illnesses should be treated. eSP showed a summarized, statistical overview of how the patients' treatments were being conducted in comparison to the standard guidelines. The comparison could increase the quality of treatment a patient received. Work for the health personnel could become more efficient with the system, because it could calculate statistics and compare the

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[1] http://www.nasjonalikt.no/

[2] http://www.helsenorge.no

[3] Agency for Public Management and eGovernment (Direktoratet for forvaltning og IKT)

[4] http://ehin.no/

[5] http://www.ntnu.no/helsit

results against the standards set by the hospital. The system was presented at a conference in 2014[6]. Here, it was presented how they developed the best treatment processes for the guidelines. After studying other reports and receiving input from medical experts, standardized patient trajectories were developed.

4.2 THE DESIGN WORKSHOP

The workshop conducted for this project consisted of two participants. The workshop resulted in a discussion instead of dividing into smaller groups to discuss among themselves. Opinions and comments were discussed and all key points were noted. Feedback on the design of the timeline was the goal of the workshop. However, the two participants did not feel comfortable to come with comments on how the system should be developed. The workshop consequently resulted in few comments on how to incorporate the guidelines into the timeline. Instead, the two participants commented on the timeline and the guidelines separately and more on the content of the system instead of its appearance. The participants were shown the guidelines presented as a timeline and as a flowchart, mentioned in Section 2.3.3. Some topics and comments discussed during the workshop are listed below.

- **Stroke Guidelines as a timeline**. St. Olav's Hospital developed the guidelines illustrated as a timeline. It was not clear how all aspects in the timeline related to each other. The participants shared a couple of comments on how to improve it. The language used in the guidelines was difficult to understand.

- **Necessary information**. Everyone has the right to see his or her own health journals. An explanation of the different diagnoses was asked for. Additionally, illustrating how long a patient has left of a specific treatment would be useful. Both participants were also coherent on the importance of showing what may happen in the near future, and that the stroke guidelines may help in doing so.

- **Guidelines as flowchart versus timeline**. The timeline looks better, but the information is better in the flowchart. There should be a better explanation of where a patient is located through the guidelines (for example getting services from the hospital or from their municipality).

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[6] http://www.ntnu.no/helsit/helsit-2014

- **Comments to the workshop**. They agreed there should have been more participants present to get more versatile information.

The design workshop conducted by Gry Seland resulted in various feedback. The participants discussed what should be presented to the patient in order to recognize themselves in their own health trajectories. The response was the date of the contact, the reason for the visit, and the results of the visit. Furthermore, related contacts should be possible to link together to clearly show the relation between them. Additionally, different contacts should be clearly disassociated from each other. Another interesting result was the participants wanting the patient to be able to see the services they did *not* receive during a particular treatment. The patients could become more critical and aware of their received treatment, after seeing standard services not given to them. Asking the doctor why they did not receive a certain service can give the patient a better understanding of the doctor's decisions and strengthening the relationship between them.

4.3 IMPLEMENTATION

The area of use for EHRs is changing. From the old key factors of storage, retrieval, and exchange comes the new factor of usability (Kopanitsa et al. [2013]). The data stored in the EHRs is now being used to gain new knowledge and insight into patients and diseases. For this master thesis, the focus is providing insight to stroke patients into their own health data. Previously, EHRs were mainly accessible by clinicians to aide them in treating patients. Research showed the advantage of including the patients, which could improve health care and patient empowerment (Van't Riet et al. [2001]). The system needed to be properly developed in order to accomplish the insight. In this chapter, the functions of the final system are introduced. Decisions were made based on the methods in Chapter 3 and the literature review mentioned in Section 4.1.

4.3.1 *Timeline Features*

Too much data can lead to the user getting lost, known as the "information overload problem" (Keim et al. [2008]). To handle large amounts of data, there should be some viewing features present to look at the data in different ways.

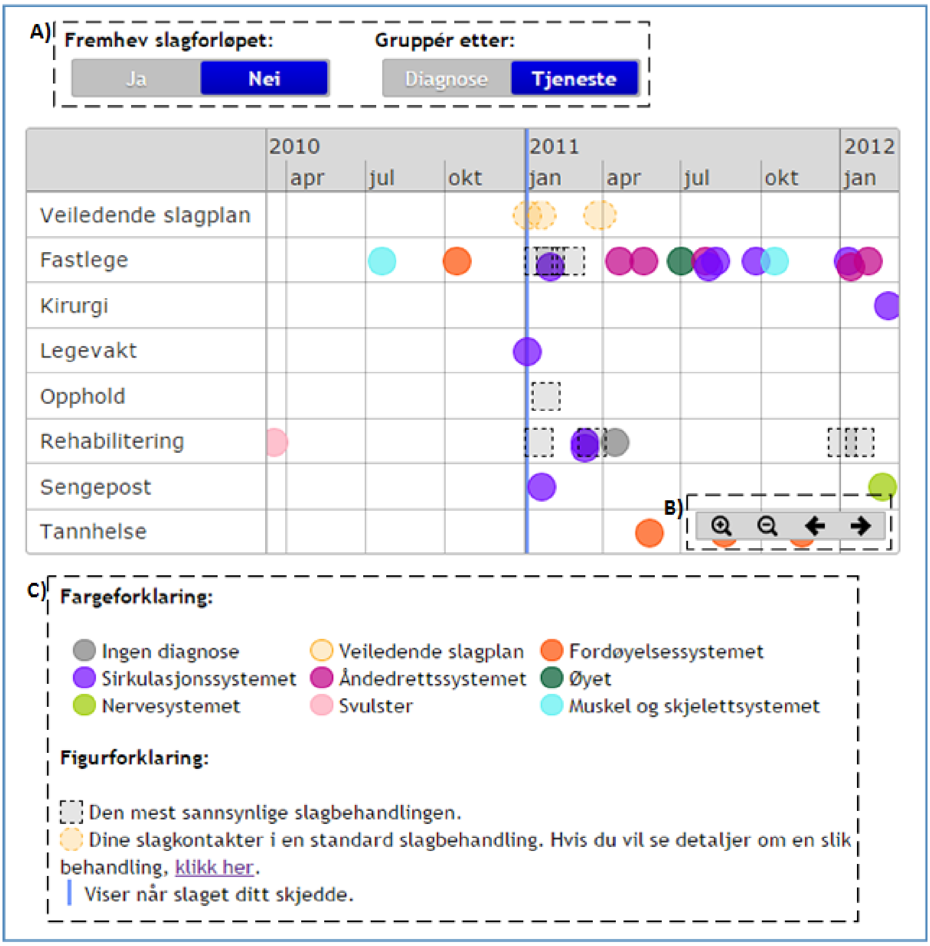
The Visual Information Seeking Mantra has the following points, and some are present in the system

- **Overview:** First presented with all contacts in the timeline
- **Zoom:** Move focus to certain contacts
- **Filter:** Highlighting of specific contacts
- **Details-on-demand:** Pop-up windows
- **Relate:** Temporal relations between contacts
- **History:** Not supported
- **Extract:** Not supported

The first thing the user was presented, was the overall timeline containing all contacts within the two-year period, shown in Figure 11. Two filtering options were provided above the timeline (see ″A)″). The options marked with blue, are the options presently selected for the illustration. A toolbar was present to help the user navigate in the timeline (see ″B)″). There were restrictions on how far the user could zoom in and out and navigate into the past and future. It prevents the users from having difficulty finding their way back to the contacts. In addition, the meaning behind the colors and figures are explained (see ″C)″).

Grouping events and giving details on-demand are visualization methods preferred over data illustrated as the doctor′s hand written notes (Kopanitsa et al. [2013]). The user could more easily draw conclusions and see similarities. Two different views were present in the system, showing similarities between the contacts in two different ways, shown in Figure 13. The first view is grouping contacts in lanes by their diagnosis, while the other is what kind of service group the contacts belong to. While the user is in the service view, the diseases were still illustrated by the color-coding of the contacts. Details-on-demand was accessible by moving the cursor over the various contacts in the timeline, shown in Figure 12. The pop-up window was visible while the cursor hoovered over a contact.

Stroke contacts should easily be identified in order to give insight into a patients′ stroke treatment. In the timeline, the user could choose to highlight the stroke treatment. The other contacts were visualized as a circle with no fill color, as seen in Figure 13. The user can still see the overall trajectory while study-



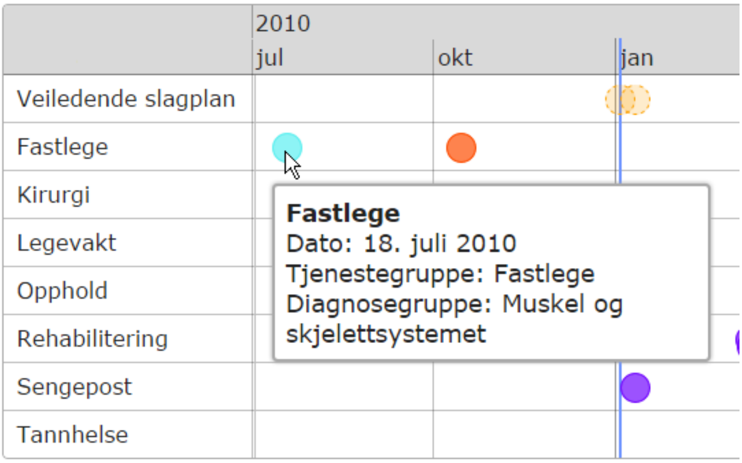
Fargeforklaring:

- ● Ingen diagnose
- ● Sirkulasjonssystemet
- ● Nervesystemet
- ○ Veiledende slagplan
- ● Åndedrettssystemet
- ● Svulster
- ● Fordøyelsessystemet
- ● Øyet
- ● Muskel og skjelettsystemet

Figurforklaring:

⬚ Den mest sannsynlige slagbehandlingen.
○ Dine slagkontakter i en standard slagbehandling. Hvis du vil se detaljer om en slik behandling, klikk her.
| Viser når slaget ditt skjedde.

Figure 11: Overview of the timeline



Fastlege
Dato: 18. juli 2010
Tjenestegruppe: Fastlege
Diagnosegruppe: Muskel og skjelettsystemet

Figure 12: Window showing additional information

ing the stroke treatment, since the other contacts were not removed completely.

4.3.2 *Incorporating Probable Contacts*

Another important topic was the display of possible future contacts to a person. Probable contacts were identified by using the methods explained in Section 3.4.4. How far a patient had come in their stroke treatment determined if the contacts showed the future or not. Table 12 shows the service groups having the highest averages of contacts present during the stroke treatments (the average found in step 4 in Table 7, Section 3.4.4). Rehabilitation and GP are the services who had appeared most frequently in the stroke treatments, and their corresponding graphs are illustrated in Figure 14. The differences between the age classes are visualized in the graph. Age class 1 (AC1) (ages 17-66) had significantly more rehabilitation at the start of the stroke treatment in comparison to the other two classes. Additionally, the age class showed a distinct decrease through the period, suggesting these patients had a shorter stroke treatment. In the GP graph however, the amount of contacts were evenly distributed among the age classes. The results in Table 12 were used to decide what would be illustrated in the timeline. The averages of each service group stated the number of days to be illustrated from each service. For example, AC1 had an average

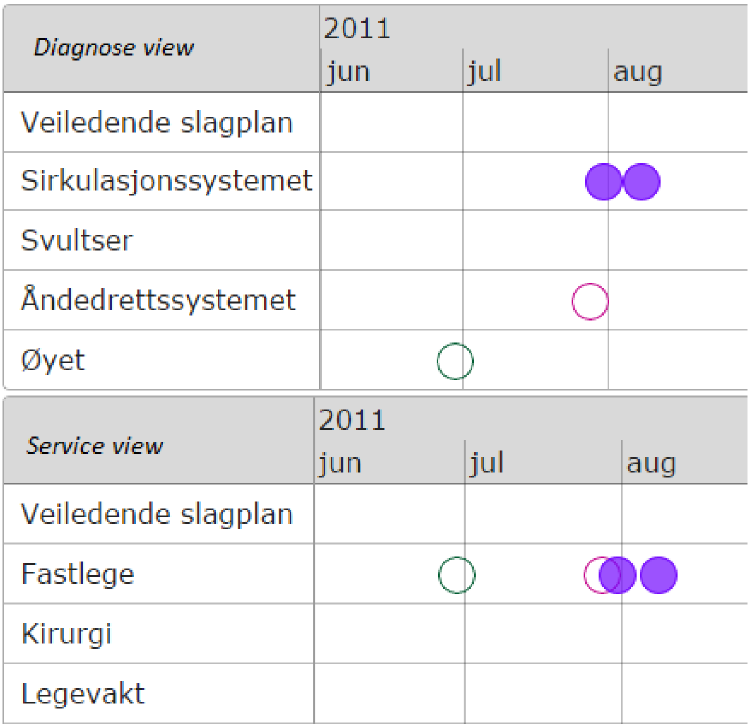


Figure 13: Two views the user can switch between

Service group	**AC1**	**AC2**	**AC3**
Rehabilitation	5.30	4.18	2.08
GP	3.61	3.26	2.68
Care facility	0.56	0.96	1.72
Assistance	0.51	0.46	0.98
Bed post	0.20	0.17	0.20
Emergency room	0.06	0.09	0.09
Housing	0.04	0.01	0.03
Monitoring	0.01	0.01	0.0
Surgery	0.01	0.0	0.0

Table 12: The uniform average for each service group

of 3.61 for the GP. The number is rounded up to 4, and the four days with the highest uniform averages were illustrated. All service groups below the average of 0.5 were excluded. This criterion led to numerous service groups not being illustrated as a probable contact. Figure 15 shows the chosen days illustrated as gray squares and with a dotted outline.

4.3.3 *Stroke Guidelines Implementation*

Letting patients compare their own stroke treatment to the stroke guidelines, could make the patient more aware of how the treatment is perceived from the health care sectors' point of view. The guidelines are developed by them, based on their experiences with stroke. The guidelines formed as a timeline from the University Hospital, were used because of its resemblance to the visualization of the patient trajectories. The stroke guidelines were placed in its own lane at the top of the timeline. The contacts in this lane were given the same color, and outlined with a dotted line, clearly showing they differ from the patients' own contacts ("Veiledende slagplan" in Figure 16). The steps of the guidelines were aligned with the corresponding contacts in the stroke treatment. Such steps can be "alert" and "rehabilitation". Figure 16 illustrates the two first steps in a particular patient's treatment. The first contact was the patient alerting about their stroke, taking place at the emergency room ("Legevakt" in Figure 16). The second step was "treatment", and this particular patient received treatment while being admitted to a stroke bedpost for three days ("Sengepost"). A pop-

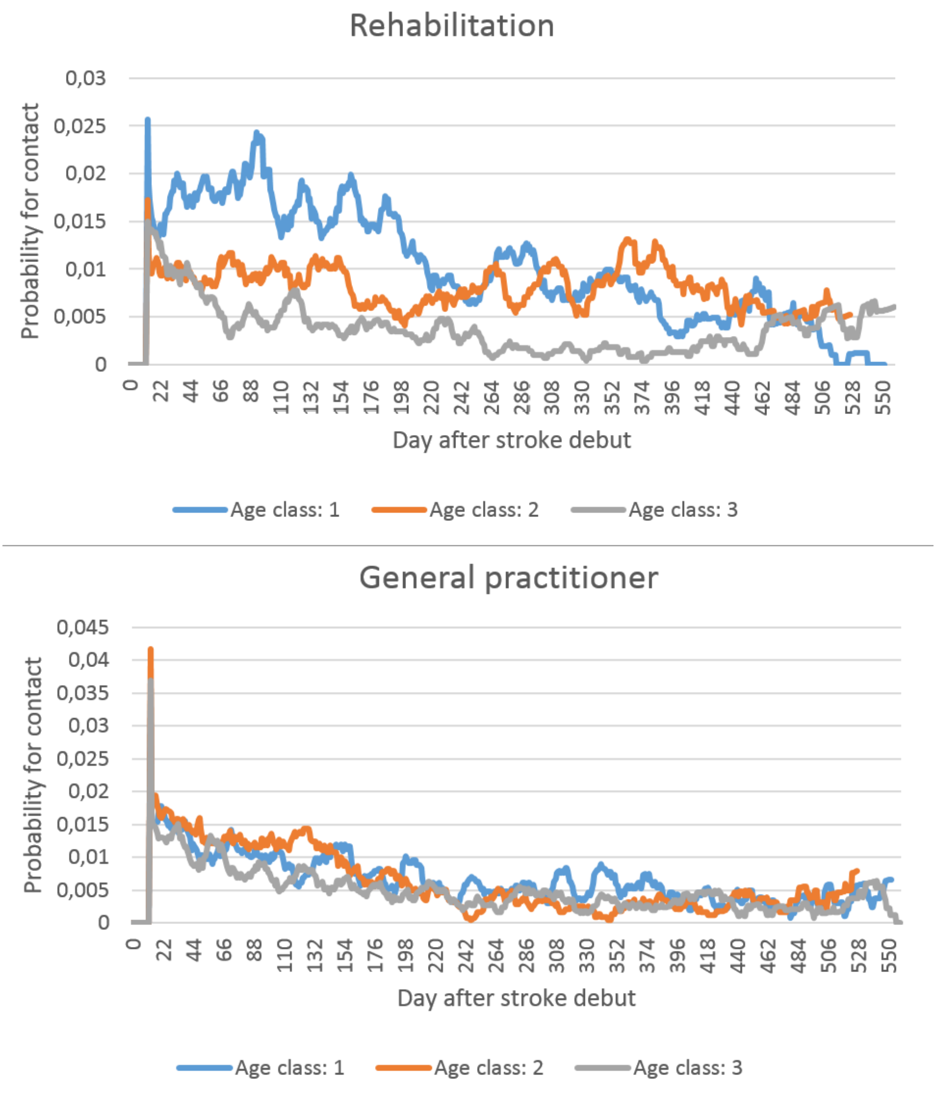


Figure 14: Graph with probable contacts

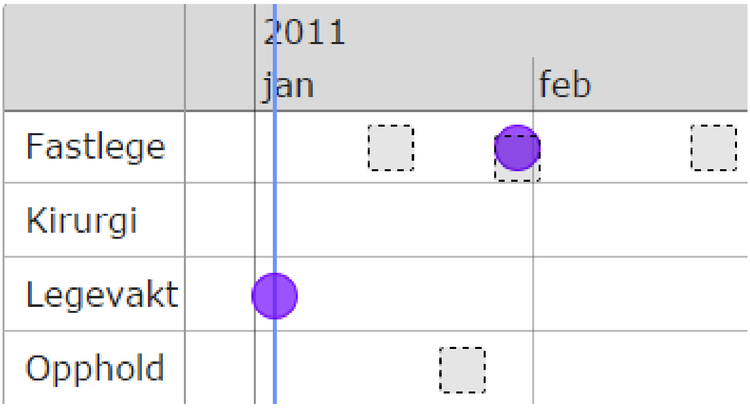


Figure 15: Probable contacts incorporated into the timeline

up window appears when the cursor is moved over the guidelines-contacts, and informs the user of the purpose of each contact in the stroke treatment.

From the design workshop led by Gry Seland, the participants agreed it would be beneficial to give additional information about a certain treatment in the timeline. For the cancer patients, it could have been information about radiation injuries, and what help exists for the injuries. For this project, extra information about stroke is given in the form of a hyperlink. The hyperlink opens a web-page with the stroke guidelines developed by the University Hospital, discussed in Section 2.3.3.

4.4 TEST RESULTS

The system was tested using A/B testing, where the testers were given six tasks to complete. Twenty testers participated all together, and were divided into two groups to test the two versions of the system. Table 13 shows the testers' information for both groups.

4.4.1 *Questions to the Tester*

The testers were asked three questions about their own experiences (see Table 9 in Section 3.5). The questions were formulated in a way so the testers could

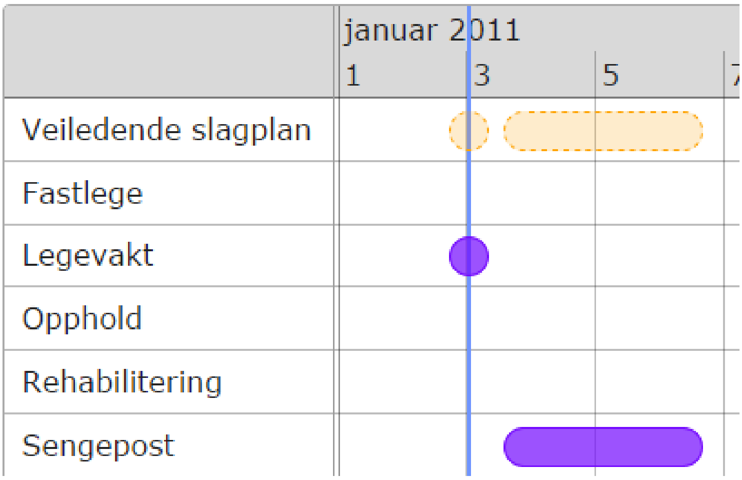


Figure 16: Visualization of the stroke guidelines

	Color	**Gray**
Age average	38.6	39.5
Gender M/F	6/4	6/4
Computer competence average (1-5)	4.3	4.2

Table 13: Statistics for the test groups

Accuracy	**Number of testers**
Exact date	4
A week	5
A month	8
A year	3

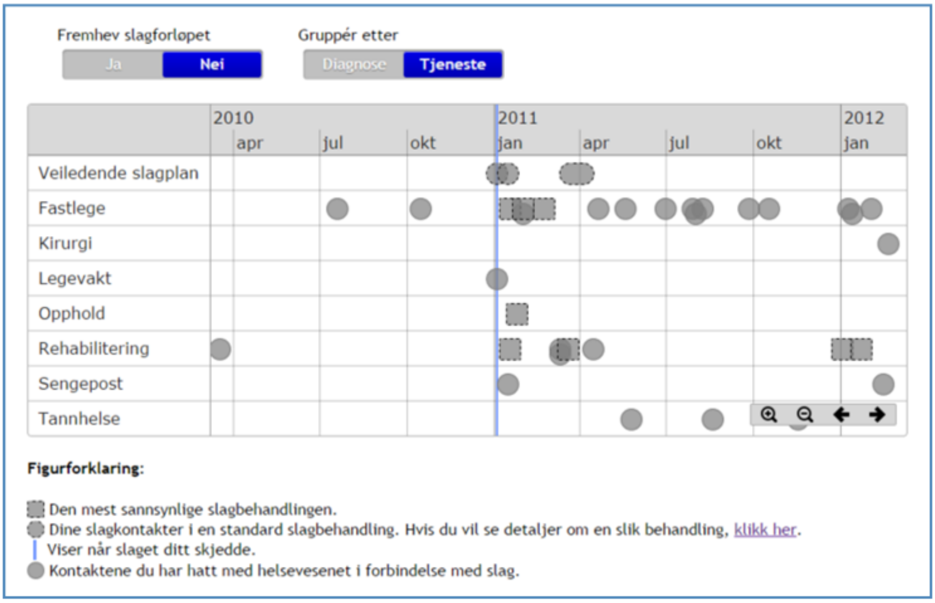
Table 14: Testing question 1 - answers

answer without revealing any sensitive information about themselves. Instead, they gave insight into their methods for keeping track of their own medical history. The first question asked if the testers could remember their last visit to the GP. Table 14 shows how accurate the answers were. All testers answered based on what they could remember, and did not look for the answer in some form of calendar. As a follow-up question, they were asked if they would be able to find the exact date, and 3 out of 16 testers (excluding the four who already knew the exact date) answered yes. For the second question, the testers were asked to remember how many illnesses they had the last year. No tester had more than two illnesses, therefore the question was easy to answer. The last question asked how many times the testers visited their GP in the last three months. The answers varied, but 16 testers stated they had not visited their GP more than once the last three months. The testers who had more than one visit could not give a precise date, only an approximate time.

4.4.2 *Tasks for the Testing*

For the A/B testing, various features were considered for the testing, but only one specific feature was chosen. One version of the system had color-coded contacts, shown in Figure 11. In the other test version, all the contacts were the color gray, see Figure 17.

The testers were asked to complete six tasks (see Table 10 in Section 3.5). The focus of the tests were to see how many of the testers used the different features in the system. It was noted when each tester used the features for the first time to find the answers to the tasks. All 20 testers understood the timeline during the first question, where they were asked to find the date of the last GP-contact. 17 out of the 20 testers did not answer correctly at first, because they had not discovered the pop-up windows. After being told to look again, all testers were able to find the pop-up window and answer with the correct exact date. Three



Figurforklaring:

▨ Den mest sannsynlige slagbehandlingen.
⬣ Dine slagkontakter i en standard slagbehandling. Hvis du vil se detaljer om en slik behandling, klikk her.
| Viser når slaget ditt skjedde.
● Kontaktene du har hatt med helsevesenet i forbindelse med slag.

Figure 17: A/B testing - the gray timeline version

Task	Color-testers	Gray-testers
1	2	3
2	1	2
3	7	4
4	0	1
5	0	0
6	0	0

Table 15: Testing feature - Diagnosis/Service grouping

more features are shown in the following tables, with details about when the testers first discovered the features during the test. The first feature was the grouping of diagnoses and services in separate views, listed in Table 15. The diagnosis-view was showing when the testers received the system. Five testers discovered they could change the view, making it easier to find the last GP-visit. The testers who had not changed the view, had some difficulties in task three when asked to tally the number of GP-visits over a longer period. Many looked for some form of help in the system, and found they could change to the service-view. This resulted in 11 out of 20 testers discovering the service view during task three. The resulting nine testers checked the pop-up windows of each contact to find the answer.

Another feature was the toolbar, which let the user zoom in and out, and move left and right in the timeline (the results can be seen in Table 16). A tester was also listed as using the toolbar feature if they navigated through the timeline with the help of the cursor (scrolling up and down). For task two and three, most testers were able to find the answer without the need of navigating around in the timeline. It was, however, a helpful tool for task three and five. The range in the months when first viewing the timeline were January, April, July, and October for each year, making it challenging to count the number of contacts within a specific month. 11 testers found the zoom-function while completing task three, and were able to see the months January to March of 2011 more clearly.

The last feature was highlighting the stroke-related contacts. This feature was placed beside the viewing-feature and resulted in seven testers finding it before they needed the feature. The discoveries of the feature were not registered, only when the feature was used to find the answer to a task. Therefore, all testers found and used the highlighting feature while completing task five. The

Task	Color-testers	Gray-testers
1	1	2
2	2	2
3	6	5
4	0	0
5	2	1
6	0	0

Table 16: Testing feature - toolbar navigation

reason why all tester found the feature was because the feature was essential to complete the task.

The guidance underneath the timeline was another element in the system. The color explanation was used on the second and fourth task by eight out of the ten testers of the color-version timeline (the gray version had no color explanation). The figure explanation was present for both versions of the timeline, but was not as helpful. 15 testers read the explanations, but had difficulty understanding the difference between the various figures, especially when asked to identify all the stroke-related contacts. Furthermore, four short topics were listed: *help*, *stroke trajectory*, *grouping possibilities*, and *shapes used in timeline* underneath the color- and figure explanations. More information could be found in these sections if the testers had difficulty understanding the timeline. Six out of 20 testers managed to complete the tasks without reading these sections. The remaining 14 read all, or part, of the sections, with varying results. Five found the help they needed, while the rest did not.

4.4.3 *A/B Testing*

The evaluation of the test results was done by following the steps proposed in Table 11 in Section 3.5. The sample data used was the time the testers used to finish the steps, and the score they gave the system in the SUS survey. The time was converted into seconds, and the SUS survey gave a list of scores ranging from 0 to 100 (not to be mistaken with percentages). The first step in the t-test was to propose a null hypothesis ($H_0 : \mu 1 = \mu 2$), meaning the average time the testers used would be equal, and the average score was equal for the two versions of the system. The two alternatives of the hypothesis were both

	Color-testers	**Gray-testers**
Average (μ)	84.95	66.85
Variance (s)	58.47	197.78
Sample size (n)	10	10
Pooled variance (s_p^2)	128.13	
Degrees of freedom	18	
T-statistic	3.576	
T-threshold	2.101	

Table 17: Result of Student's t-testing - SUS score

	Color-testers	**Gray-testers**
Average (μ)	567.1	704.6
Variance (s)	24 750	16 271
Sample size (n)	10	10
Pooled variance (s_p^2)	20 511	
Degrees of freedom	18	
T-statistic	2.147	
T-threshold	2.101	

Table 18: Result of Student's t-testing - Time

evaluated. Table 17 and Table 18 shows the variables used, and the result of step 2 and step 3 of Table 11, for each alternative separately.

The final step was to compare and evaluate the t-statistic with the t-threshold. For both alternatives, the statistic was greater than the threshold, and the hypothesis could be discarded with a confidence level of 95%. The A/B testing proved that the version of the system with color had both better usability (better score on the SUS survey), and the testers completed the task faster. A system with a score above 70 is considered an acceptable system (Bangor et al. [2009]). The gray version received a score of 67 (see Table 17), and is not considered an acceptable version of the system. The colored version received a SUS score of 85, meaning it has excellent usability.

5

EVALUATION

Throughout the project, various methods have given valuable results. Some results were not as expected, due to changes happening during the project. A better understanding of the project is given, by discussing and evaluating the results and the changes. Section 5.1 mentions deviations from the project plan and the effects it had on the overall result. Changes in the workshop are discussed in Section 5.3, followed by an evaluation of the system implementation (Section 5.4). The final section, 5.5, discusses the testing of the system.

5.1 THE PROJECT PROCESS

In retrospect, this master thesis was largely completed as planned. The Gantt chart in Figure 5 was followed, except for some tolerable delays. The testing was conducted one week later to better fit with the time schedules of the testers and the development phase was extended accordingly.

5.2 THE LITERATURE REVIEW

The developed system takes into account important aspects of the literature review. In Section 4.3, the system was compared to the Visualization Mantra to see how the features of the system comply with the mantra. Not all features were supported in the timeline. The history feature could be useful if the user was allowed to alter the timeline. The alteration could be the removal of contacts or letting the patient submit their own comments into the system. Similarly, the extraction feature was not needed, because the user cannot extract any more information than what is already shown in the two viewing features (see

Figure 13). The last feature of the Mantra was extraction, and is only supported in the system by letting the user highlight the stroke-related contacts. The user is not able to conduct any extractions of their own. Important characteristics of the data were also identified in Section 4.1.1 (Aigner et al. [2008]). The data was based on linear time, and consisted of both time points and time intervals. The contacts also follow an ordered time, making it straightforward to plot them into a timeline. Being aware of the characteristics helped deciding how to visualize the data. Rind et al. [2010] state some criteria for their study, consisting of 14 EHR visualization systems (see Section 4.1.2). The first criterion stated that the data had to consist of the complete patient histories. The criterion was not realized, because the dataset for this master thesis only covers a two-year period. The system supports the second criterion, using discrete non-spatial data. There were no accurately referenced locations in the data, only hospital wards and names of services. The third criterion mentioned interactivity. This was an essential part, letting the users interact with the system. The last criterion was not fulfilled, because this system was not developed for the benefit of the health care personnel.

There is a positive trend in Norway, and many contributors are involved in enhancing the quality of sharing medical data. Seeing the enthusiasm for this area of work can be of great motivation for future projects. The focus on patients is also becoming more evident, leading to more patient empowerment (Johnsen and Bankauskaite [2006]). As mentioned in Section 4.1.3, there is much focus on giving patients access to their medical data, and also making sure it is understandable for the patients. A considerable part of the DIS-project is to show the trajectories in a timeline to the citizens of Norway[1]. The timeline developed in this master thesis corresponds to this part of the DIS-project, and is therefore relevant to the developments within the health care sector.

5.3 THE DESIGN WORKSHOP

The workshop consisted of only two participants. The number should have been larger, giving a wider range of feedback and opinions on the topics discussed. However, with only a few participants, the workshop was able to focus more on each participant. Both participants belonged to organizations focusing on patient care, and gave valuable feedback.

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[1] http://www.helsenorgebeta.net/2015/01/forprosjekt-digitale-innbyggertjenester-i-spesialisthelsetjenesten/

The workshop conducted by Gry Seland focused on presenting medical information to the patient it concerned, which is a similar topic as this master thesis. The main difference was the focus group: cancer patients versus stroke patients. There are some commonalities between the groups, since both diseases are chronic diseases. Therefore, the results from the workshop by Gry Seland can be used for this project. The cancer patients stated they would like to have illustrated the contacts connected to a particular sickness, and it may be assumed the same goes for stroke patients.

5.4 IMPLEMENTATION

It is important to have the planned user into the loop in the early stages of development. The system can only be successful if the users' needs are addressed and finds the system valuable (Van't Riet et al. [2001]). For this master thesis, stroke patients did not participate in the planning of the system. Instead, other people with experience from the health care sector gave feedback. It would have been wise to have additional rounds of development and testing, so changes made to the system after one round could have been evaluated by a new group of testers.

Contacts concerning the same diagnosis were given the same color in the timeline to make the similarity easy to spot. Colors alone is not enough, since a large proportion of men are color blind (10%). For color blind users, they could identify the similarities between contacts by changing to the diagnosis-view instead of the service-view. Additionally, the diagnosis information is shown by hovering the cursor over the contacts.

5.4.1 *Data Selection*

There were two difficulties with using medical data. First, the format the data was stored in varied depending on the source. Second, the format medical data are stored in within one source, can change through the years. This presents problems when developing an automated visualization of clinical data, when there is a constant possibility of the data changing (Bettencourt-Silva et al. [2012]). The dataset used consisted of data from three different sources. The system would not work properly if the dataset was replaced with new data and new formats. Another difficulty with medical data is visualizing the information stored in narrative, unstructured data written by the doctors (Thiessard et al. [2012]). Only structured, computer-stored data was used in this project, which may have resulted in important data being omitted from the timeline. The data should be made into structured data in order to easily visualize all the medical data, instead of developing a system capable of interpreting all the unstructured data it may be presented.

The dataset

The dataset received from the PAsTAs project was de-identified and partially anonymous. The dataset was made 5-anonymous by generalizing the contacts before it could be shown to the users of the system. The data needed to be anonymous since it was shown to various users, and not the person it concerned. This was also the reason why there was little focus on security and ensuring a particular patient that his/her own sensitive data was secure.

The limitation of details in the dataset made it difficult to satisfy the patients' desire to see all the information stored about themselves (Research Question 2, RQ2). The testers seemed satisfied with the current system when studying the results of the usability testing. The testers may have changed their minds if they had been shown another version of the timeline with more details. In order to identify how much information the testers would have liked to see in the system, fictive information could have been added to the system. The information could have been lab results, doctor's notes, or an image from a CT scan. People seemed to want access to as much information as possible, as mentioned in the workshops and the literature review (Wågbø [2014]).

Identifying stroke treatment

For this master thesis, the stroke patients were examined when being aligned by the stroke debut. The method for finding the debut resulted in the removal of 459 PIDs, see Section 3.4.1. Another method could be to study the ending point of the treatment. The challenge with a chronic disease is the absence of a clear ending point, or having an ending point at all. According to the stroke guidelines, all patients have to visit a polyclinic health care facility one to three months after the stroke to analyze how the recovery has been so far. Such a contact could be used as the alignment point in the end of the stroke treatment. Unfortunately, the challenge with the dataset is the limit of the two-year period. Consequently, just like the starting point, the polyclinic contact may be located outside the range of the dataset. A patient may have had multiple visits with the polyclinic, making it difficult to know which one to use as a comparison.

The diagnostic code systems

The diagnostic code registered for a contact cannot always be relied upon. Occasionally, when a patient is visiting their GP, the GP may register the visit with the same diagnostic code used for the previous contact, even if it is not correct. A person may not recognize their own trajectory if this is the case for multiple contacts. For this project, the diagnostic codes were assumed correct, and not critically assessed. The focus was on how to visualize the data in a helpful system, not analyzing how correct each diagnostic code was.

Every contact with a main diagnosis corresponding to a stroke diagnostic code (see Appendix D), was included in the stroke treatment of the particular PID. A few uncertainties were uncovered about the contacts, when studying the PIDs' stroke treatments. Some PIDs had single stroke-related contacts spread across their trajectory, with little connection between them. Consequently, some stroke-related contacts were viewed differently than the rest. For instance, a patient visits their GP and think he/she has suffered a stroke. The visit is registered with a stroke-related diagnostic code, and the patient is urged to go to the emergency room. Here, it may be concluded that it was a false alarm. The registered contact at the hospital may receive the correct diagnostic code, while the GP contact would still have the stroke-related diagnostic code. The patient may end up in the project's dataset without ever having suffered a stroke, because of the GP contact.

5.4.2 *Grouping of Similar Contacts*

Some of the diagnostic groups shown in the timeline were too vague. Diagnostic group T in Table 5 is called "abnormal findings". Showing a contact marked with this label could confuse the user, instead of reminding them of what took place during the specific contact. It would have been possible to provide a more detailed description of the contacts if the complete diagnostic codes were shown in the dataset. Unfortunately, the information would not have been anonymous enough. Similarly to the "abnormal findings" label being too vague, showing the detailed label for a diagnostic code could be too difficult for a patient to understand. The diagnostic codes should be made more understandable for people without a medical background.

5.4.3 *Grouping of Comparable Patients*

Three possible criteria for grouping patients were mentioned. Grouping patients together based on their previous medical history was not possible because it was not possible to get a holistic view in the two-year period of the dataset. Functional level would also have been difficult to use, because of the challenge of identifying it in the data. Age is the only criteria clearly identified for each PID.

Using ADL would have been a good solution for grouping patients together. Unfortunately, there are few contacts describing the functional level. Without such attributes, it is challenging to express how functional the patients are after their stroke. A functional level scale is needed. Developing a system is difficult when it is uncertain what variables a patient will have in their trajectory. Here, exception handling would be necessary to decipher and depict what functional level the unknown variables would belong to. The exceptions can have a great impact on the system's efficiency and effectiveness (Panzarasa et al. [2002]). A possible method for grouping patients based on functional level without needing so much exception handling is dividing patients into two groups: patients with no variants of assistance after discharge and patients with assistance present in their trajectories. Unfortunately, the method would result in only two groups with high divergence in each.

5.4.4 *Probable Contacts*

For the identification of probable contacts during a stroke treatment, an average number of contacts were calculated for each day. To calculate the average, the end of the treatment for each patient had to be defined. There could be several reasons why a patient's treatment ended. The patient could have been declared healthy and be finished with his/her treatment, the patient could have died, or the patient could have reached the end of the two-year period of the dataset. In the system, the possibility of a patient dying was not taken into consideration, since a death was not marked in the data. A solution to the problem could have been to add a mortality rate, and remove a percentage of the PIDs each day when calculating the daily average. Finding the correct death rate for patients dying within the two first years of their illness proved to be difficult. Due to this, there was no distinction between patients dying and patients becoming healthy. As a result, the probability of a contact was higher than what would actually be the case.

In the final version of the system, the percentage for each probable contact was not shown to the users. Having a percentage to the contact might have given the users a point of reference. With averages around 2% (seen in Figure 14), the numbers were too low to have much meaning to the users. Instead of percentages, a scale could have been presented. The scale could have been divided into high, medium, and low probability, where the time intervals were marked with the appropriate value.

Finding probable contacts for each age class separately was done because the average patient at different ages have a dissimilar form of treatment. This is seen in Figure 14, where there were clear differences in the amount of rehabilitation the three age classes received. While the youngest group (AC1) had more rehabilitation at the beginning of the stroke treatment, the two other age classes had a more uniform graph. The grouping by age gave the patients probable contacts, which were personalized towards their typical treatment. The division of patients into age classes made AC1 contain patients between ages of 17 and 66 years. While a difference of 49 years is considerable, it gives a better probability than the arbitrary result only a few patients would have given (for example the 26 PIDs present in age group 6, see Table 6).

As mentioned in Section 4.3.2, some of the testers had difficulty understanding the difference between the probable contacts and the contacts belonging to the current patient's trajectory. The difference must be clear for the user of the system if the probable contacts are to fulfill their purpose. There may have been less confusion if the testers had receives an introduction prior to using the system. The system was intended to be self-explanatory and not be dependant of any assistance, and this is why no thorough introduction was given. Two out of the 20 testers suggested separating the patient's trajectory from the guidelines and the probable contacts, while still maintaining the match between the contacts. Figure 18 shows how the contacts could be separated and still maintain the relations between the various contacts.

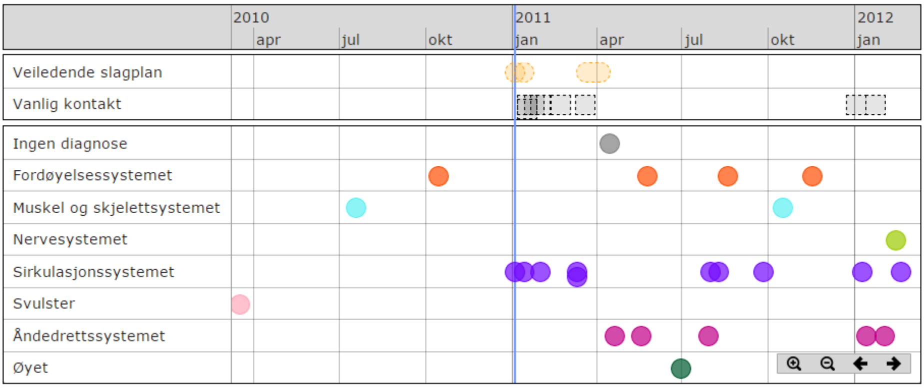

Figure 18: Example of a new version of the timeline

5.4.5 *Stroke Guidelines*

The stroke guidelines in Figure 19 illustrated information as branching time, because there were different routes the patients could take (Aigner et al. [2008]). Few visualization techniques exist for this kind of data. Incorporating the guidelines into a timeline with linear time data became a challenge. After studying the dataset and the contents of the stroke guidelines, the problem was solved. The branching time data was avoided, because multiple steps in the stroke guidelines were merged together into the single contacts present in the patients' stroke treatment (see Section 4.3.3).

5.5 TESTING

The people who tested the system were not chosen based on their medical history. The optimal solution would have been to test the system on stroke patients and show them their own data in the system. The solution would have made it possible to test the features connected to the stroke treatment more thoroughly. The two participants of the design workshop also gave recommendations to speak with stroke patients and get their opinions on the developed system. Unfortunately, the REK application required to get in contact with real patients, would take too long to be approved.

The testers were to be between the ages of 20 and 85. Three testers above the age of 80 were tested, and some challenges were uncovered. The testers had limited experience with computers and could not use the system to its full potential. The conclusion was that the system required a higher comprehension of computers than originally planned. One of the testers over 80 had an iPad and was more comfortable with it than the computer. A solution could have been to display the system on multiple devices. The system should be implemented in a way which lets the user operate the system without the help of a computer expert (Plaisant et al. [2008]). After testing the three people over the age of 80, it was decided to lower the age of the testers, resulting in the oldest person being 65 years old.

Execution of the tests

The testers submitted similar answers on the three questions about themselves. For question 1, the testers could have been asked to find the exact date of their last GP-contact while the time was recorded. The time results could be compared to the time it took to find the last GP-contact in the system, hopefully resulting in a faster time when using the system. All testers had little difficulty answering question 2 and 3, because they did not have multiple illnesses or constant contact with the health care sector. The answers to the questions would have had more value if the testers had a chronic disease.

Only 3 out of 20 testers read the guidance under the timeline before they started with the tasks. In retrospective, a majority of the testers admitted to it being been wise to have read the text before starting. The text gave more information about the stroke guidelines, the probable contacts, and the contacts connected to the PID. It was also mentioned that some of the text was difficult to understand. Most of the confusion was associated to the stroke guidelines and the probable contacts. The difference in the shape and color was insufficient, when trying to understand the contacts were not ordinary contacts in the PID's own trajectory.

Each tester was asked to complete a SUS survey. The survey gave an indication of how usable the system was. The results of the SUS survey cannot be trusted completely, even if the system receives a high score. The testers are asked to be objective when they completed the survey, but they may give better scores because they do not want to be too harsh. Even if some scores may be slightly higher than what they should be, the score can give a pointer on how the system is perceived. The colored- and gray-version of the timeline received the scores 85 and 67, respectively. Although the testers gave better scores than they should have, there was a clear difference in the two SUS scores, and it was concluded the colored-version to be the best version.

6

CONCLUSION

The establishment of EHRs provided a helping hand to the health personnel when documenting medical data about a patient. Subsequently, EHRs contain large quantities of interesting data, which would have been overwhelming to gather and analyze in earlier years. Storing medical data electronically has opened up for new possibilities to exploit the data. Such areas of use can be aiding health personnel in making good clinical decisions or studying the data to gain new medical knowledge. Countless systems have been developed with the goal to make utilization of the EHRs effortless for clinicians. Through this process of developing new and improved systems, a group of people has not been focused on as much as they should have been. Even though patients have the right to see their medical journals, few systems have been developed to help patients fully understand their own medical history. This master thesis has focused on the patient and how medical data can be illustrated to give patients an overview of their own trajectory.

6.1 ANSWERS TO THE RESEARCH QUESTIONS AND HYPOTHESIS

The research questions (RQ) and the hypothesis should be revisited to evaluate the accomplishments of this master thesis. They are introduced in Chapter 1.

RQ1 asked how the situation is today for visualizing medical data. Based on the literature review, important characteristics of visualization were analyzed. The results were important when dealing with the medical data and trying to visualize it.

RQ2 wondered what kind of medical information a patient should be shown. For this master thesis, data was presented in the timeline. However, the data was limited. According to the workshops, it was clear the patients would like more information. Test results and what was discussed in various consultations, should be shown as well.

The third and last research question was composed of three parts. The three parts were the individual trajectory, the stroke guidelines, and the grouping of patients. The question was whether the components should, and could, be incorporated into the same visualization. Illustrating an individual trajectory was the basis for the timeline, and the other two parts were meant to build upon this trajectory. The stroke guidelines were mapped to the single trajectory, and shown in a separate lane in the timeline. Similarities between the patients' contacts were found by looking at a group of comparable patients. The similarities were used to present probable contacts most likely to take place. RQ3 asks whether it is useful or not to show the three components together. According to the results of the testing, the current system was not optimal, and multiple testers had difficulty understanding the stroke guidelines and the probable contacts without receiving help. Nevertheless, to congregate the three components together has proved to be useful through the literature review and the workshops.

The hypothesis was derived from the research questions. Through the literature review, workshops, and testing, it was attempted to disprove the hypothesis. The first part of the hypothesis (patients wish to use a digital system to get an overview of their own health situation) was strengthened by the advancement seen in the health care sector today. Giving patients electronic access to medical records and visualizing the records in a meaningful way, is constantly evolving. The second part of the hypothesis (patients wish to see details on-demand) was also proved, being supported by both the literature review and the workshops. This part of the hypothesis could have been considered being proved based on testing. The details in the contacts were shown on-demand in the system, but the amount of details were limited. Consequently, it would be challenging to test whether or not the testers experienced "information overload" if all the details had been given at once. Without detecting "information overload", the testers may not realize the benefit of receiving the details on-demand. In conclusion, the hypothesis has not been disproved.

6.2 CONTRIBUTIONS

Previous medical systems have been intended for clinicians and medical researchers. This master thesis focused on developing a helpful digital tool for visualizing medical data to the patients. Methods for the presentation of medical data were developed to give the patients valuable insight into their own medical history. The methods consisted of grouping similar medical data together, illustrating possible future medical contacts, and comparing patients' stroke treatments to clinical guidelines. The findings of this master thesis comply to the developments in Norway, as mentioned in Section 5.2.

6.3 FUTURE WORK

Some improvements to the system were mentioned in Chapter 5. The dataset should contain more details about the contacts, giving the patient a holistic view of their treatment. It should also be contemplated whether or not the labels used on the diagnoses and services should be altered. Not all labels were coherent for the people who tested the system. Age groups were used to group patients together. The users would be able to explore their own health situation better if they were able to alter the grouping criteria. Other criteria could be the two mentioned earlier: functional level and previous medical history. For comparable contacts, the percentages became too small and were omitted from the visualization. Another method for visualizing how probable each contact really is, should be developed.

Figure 18 illustrated an alternate solution for visualizing the three components (patient trajectory, probable contacts, and stroke guidelines). A more precise distinction between the actual contacts to a patient and the fictive contacts (the probable contacts, and the stroke guidelines) should have been developed.

It is important to ensure the users privacy when presenting sensitive data online. The demands from the patients are high, leaving little room for errors or gaps (Pyper et al. [2006]). High demands also come from the legislation, causing the development of electronic access to patient trajectories to be long and strenuous[1]. The subject of patient privacy was not addressed in this master thesis, since the focus was on the visualization of the contacts (both the patients'

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[1] http://www.telemed.no/elektronisk-tilgang-til-egne-journaldata.5072004-247951.html

own contacts, the stroke guideline, and future contacts). More secure functions should be incorporated into the system if it was to be used to present medical data to the person it concerns. An example of such a function is having the users log on to verify their identity.

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Appendices

A

STROKE GUIDELINES AS A FLOWCHART

Figure 19 was developed by The Norwegian Directorate of Health and explains the different possible paths a stroke patient can go through a treatment. The bigger the arrow, the more common the path is. All patients with symptoms of acute stroke should get to the emergency room ("Akuttmotak" in Figure 19) and then immediately be admitted to a hospital in the stroke ward ("Slagenhet"). Patients without symptoms should be checked by a doctor and based on this check-up either be admitted to the hospital (high risk) or be referred to get a more thorough examination ("Poliklinisk utredning") within 48 hours (low risk). After these two possibilities, there are a number of different paths the patient may end up following. The patient may be transferred to the specialized stroke center ("Spesialisert slagsenter") if the stroke is too extensive, but all patients will get secondary prevention ("Sekundærforebygging") and early rehabilitation while they are in the hospital. After the secondary prevention, the patients will be examined, and the most suitable rehabilitation will be decided: home without rehabilitation, home with rehabilitation, nursing home, or admitted to a rehabilitation department. Patients should also be offered a checkup ("Poliklinikken") one to three months after discharge from the hospital.

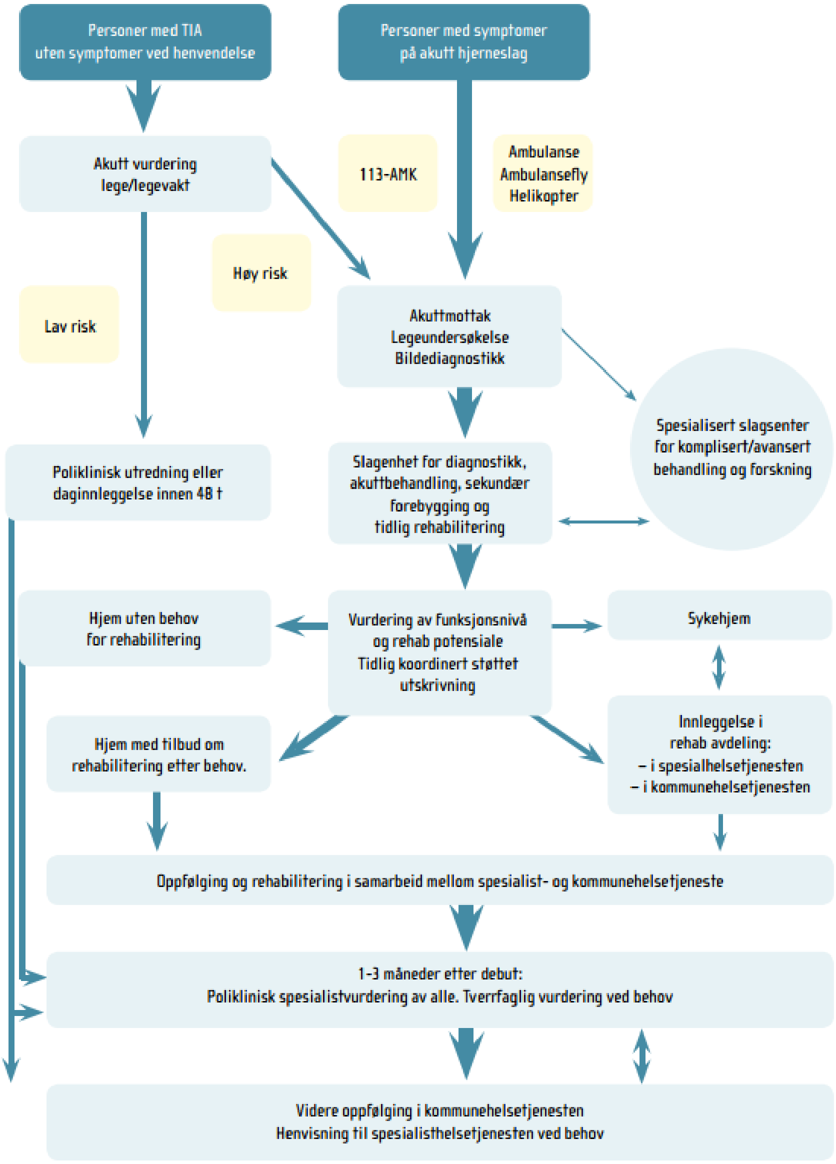

Figure 19: Stroke guidelines as a flowchart

B

STROKE GUIDELINES - ST. OLAV'S HOSPITAL

Figure 20 shows the three steps of the stroke guidelines developed by the St. Olav's Hospital.

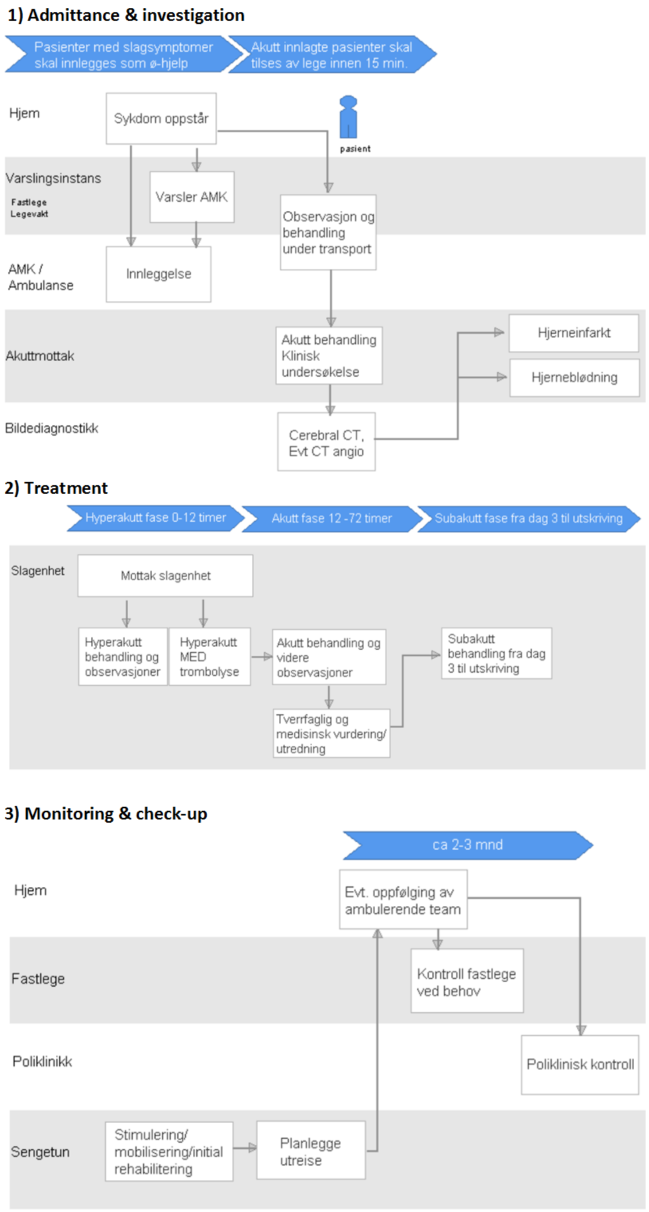

Figure 20: The stroke guidelines shown as a timeline

C

WORKSHOP INVITATION

The invitation sent out to get participants to the workshop conducted in February.

Framstilling av pasientforløp. Invitasjon til møte om brukersynspunkt

Vi inviterer personer med ulik erfaring fra kontakt med helsetjenesten til å delta på dette møtet. Det blir gjennomført i sammenheng med en masteroppgave som går ut på å finne best mulig måte å visualisere en persons helsehistorikk. En slik visualisering skal kunne gjøre det lettere å ha oversikt over de forskjellige kontaktene man har hatt med helsesektoren og dermed et klarere overblikk. Deltakere trenger ikke datakunnskaper for å delta på dette møtet.

Tidspunkt: 25.februar kl 10:00-12:00

Sted: MTS11 (Medisinskteknisk forskningssenter 1. etg på St. Olavs Hospital)
Kart til møterommet: http://s.mazemap.com/XwU4BX

Mål for workshop: Få tilbakemeldinger på hvordan en slik løsning kan se ut for å være til mest mulig nytte til pasienter og hvilken informasjon som det er viktig å videreformidle til pasienten sammen med helsekontaktene.

Plan for workshop:

- Vise en fiktiv tidslinje, i papirformat, med helsetjenester en person kan ha hatt, og la deltakerne kommentere tidslinjen for å få frem kommentarer til hvordan tidslinjen kan illustreres best mulig.
- Diskutere hvilken informasjon som er ønskelig å bli presentert i en slik tidslinje som er nødvendig for å gi en person et klart bilde av deres egen helsehistorikk.
- Vise standardiserte pasientforløp og diskutere muligheter for å vise slike forløp sammen med en pasients helseforløp.

Det vil også bli servert lunsj(baguetter) og drikke (kaffe/juice) til alle som deltar.

Gry Sundt og Ingunn Hansen
Studenter ved NTNU, Datateknikk
[redacted]
tlf: [redacted]

D

STROKE DIAGNOSTIC CODES

Two diagnostic code systems have been used to indicate the cause for the various contacts in the dataset. The ICD-10 diagnostic code system focuses on specialized health care services, such as the hospital, while the ICPC-2 diagnostic code system is used in the primary health care services, such as the GP. the diagnostic codes connected to a stroke diagnosis are listed below.

Utvalg av diagnosekoder hjerneslag 210914

icd10	ICPC2	KronikerICPC2	DESCRIPTIO	ICPC2Txt
G460	K90	K	Arteria cerebri media-syndrom	Hjerneslag
G461	K90	K	Arteria cerebri anterior-syndrom	Hjerneslag
G462	K90	K	Arteria cerebri posterior-syndrom	Hjerneslag
G463	K90	K	Syndrom som skyldes hjernestammeslag	Hjerneslag
G464	K90	K	Syndrom som skyldes cerebellart slag	Hjerneslag
G465	K90	K	Rent motorisk lakunært syndrom	Hjerneslag
G466	K90	K	Rent sensorisk lakunært syndrom	Hjerneslag
G467	K90	K	Annet lakunært syndrom	Hjerneslag
G468	K90	K	Andre spesifiserte syndromer som skyldes hjernekarsykdom	Hjerneslag
I600	K90	K	Subaraknoidalblødning fra carotissifon og carotisbifurkatur	Hjerneslag
I601	K90	K	Subaraknoidalblødning fra arteria cerebri media	Hjerneslag
I602	K90	K	Subaraknoidalblødning fra arteria communicans anterior	Hjerneslag
I603	K90	K	Subaraknoidalblødning fra arteria communicans posterior	Hjerneslag
I604	K90	K	Subaraknoidalblødning fra arteria basilaris	Hjerneslag
I605	K90	K	Subaraknoidalblødning fra arteria vertebralis	Hjerneslag
I606	K90	K	Subaraknoidalblødning fra andre intrakranielle arterier	Hjerneslag
I607	K90	K	Subaraknoidalblødning fra uspesifisert intrakraniell arterie	Hjerneslag
I608	K90	K	Annen spesifisert subaraknoidalblødning	Hjerneslag
I609	K90	K	Uspesifisert subaraknoidalblødning	Hjerneslag
I610	K90	K	Subkortikal intracerebral blødning i hjernehalvdel	Hjerneslag
I611	K90	K	Kortikal intracerebral blødning i hjernehalvdel	Hjerneslag
I612	K90	K	Uspesifisert intracerebral blødning i hjernehalvdel	Hjerneslag
I613	K90	K	Hjernestammeblødning	Hjerneslag
I614	K90	K	Intracerebellar blødning	Hjerneslag
I615	K90	K	Intraventrikulær hjerneblødning	Hjerneslag
I616	K90	K	Hjerneblødning med flere lokalisasjoner	Hjerneslag
I618	K90	K	Annen spesifisert hjerneblødning	Hjerneslag
I619	K90	K	Uspesifisert hjerneblødning	Hjerneslag
I620	K90	K	Subduralblødning (akutt/ikke-traumatisk)	Hjerneslag
I621	K90	K	Ikke-traumatisk ekstraduralblødning	Hjerneslag
I629	K90	K	Uspesifisert intrakraniell blødning (ikke-traumatisk)	Hjerneslag
I630	K90	K	Hjerneinfarkt forårsaket av trombose i precerebrale arterier	Hjerneslag
I631	K90	K	Hjerneinfarkt forårsaket av emboli i precerebrale arterier	Hjerneslag
I632	K90	K	Hj.inf. forårs. av uspes. okkl. el. stenose, precereb. art.	Hjerneslag
I633	K90	K	Hjerneinfarkt forårsaket av trombose i hjernearterier	Hjerneslag
I634	K90	K	Hjerneinfarkt forårsaket av emboli i hjernearterier	Hjerneslag
I635	K90	K	Hj.inf. forårs. av uspes. okkl. eller stenose i hj.art.	Hjerneslag
I636	K90	K	Hj.inf. forårsaket av cerebral venøs trombose, ikke-pyogen	Hjerneslag
I638	K90	K	Annet spesifisert hjerneinfarkt	Hjerneslag
I639	K90	K	Uspesifisert hjerneinfarkt	Hjerneslag
I64	K90	K	Hjerneslag, ikke spesifisert som blødning eller infarkt	Hjerneslag

E

DIAGNOSTIC CODES STATISTICS

The diagnostic codes are studied to see how many PIDs have a diagnostic code present at least once in their medical data. Table 19 shows some of the results when tallying up the number of distinct PIDs present for diagnostic codes consisting of a letter and a number. 96 diagnostic codes had less than five stroke patients present, which is below the 5-anonymity requirement. Consequently, these codes needed to be generalized more.

Diagnostic code	Stroke PIDs	Total PIDs	Diagnostic code system
Y4	1	3	IDC-10
T4	1	5	ICPC-2
D3	1	55	ICPC-2
X9	1	2 307	ICPC-2
D8	2	216	ICD-10
W7	3	7 907	ICPC-2
L6	5	437	ICD-10
I9	10	144	ICD-10
N4	48	2 247	ICD-10
G4	183	3 590	ICD-10
I6	743	1 712	ICD-10
K9	924	8 794	ICPC-2

Table 19: Some diagnostic codes and their statistics

The decision was to only use the first letter of the diagnostic codes. When merging A0 - A9 into A for ICD-10 and ICPC-2 respectively, only four diagnostic codes fell under the 5-anonymity limit (shown in Table 20). In the final

Diagnostic code	Stroke PIDs	Total PIDs	Diagnostic code system
O	4	4771	ICD-10
P	1	29	ICD-10
W	2	34	ICD-10
Y	1	3	ICD-10

Table 20: Diagnostic codes needing more generalization

timeline, the diagnostic codes of ICD-10 and ICPC-2 are merged together, creating larger groups of patients, consequently fixing this problem.

Table 21 lists the two diagnostic codes D and H within ICD-10 and their respective statistics. Some of the codes are not 5-anonymous (D0, D7, H7, etc.). However, the groups will be large enough if they are grouped together as described in Section 3.4.1. The diagnostic codes were merged into four new groups (D0-D4, D5-D8, H0-H5, and H6-H9).

Diagnostic code	Stroke PIDs	Total PIDs
D0	1	760
D1	36	2349
D2	15	4898
D3	32	1310
D4	38	1841
D5	15	284
D6	24	378
D7	2	136
D8	2	216
H0	42	2810
H1	30	2485
H2	157	6431
H3	101	3818
H4	115	6982
H5	98	3662
H6	40	2601
H7	4	384
H8	26	1105
H9	120	6241

Table 21: Codes D and H in ICD-10

F

SUS-SURVEY

The SUS, system usability scale, consists of 10 questions with five response options for each. The testers answer to what degree they agree or disagree with each statement about the system.

SYSTEM USABILITY SCALE

Age:

Gender:

Profession:

Level of computer skills (0-5):

For each item identified below, circle the number
to the right that best fits your judgment of the system.

Survey Items	**Scale**				
	Disagree				**Agree**
1. I think that I would like to use this system frequently	1	2	3	4	5
2. I found the system unnecessarily complex	1	2	3	4	5
3. I thought the system was easy to use	1	2	3	4	5
4. I think that I would need the support of a technical person to be able to use this system	1	2	3	4	5
5. I found the various functions in this system were well integrated	1	2	3	4	5
6. I thought there was too much inconsistency in this system	1	2	3	4	5
7. I would imagine that most people would learn to use this system very quickly	1	2	3	4	5
8. I found the system very cumbersome to use	1	2	3	4	5
9. I felt very confident using the system	1	2	3	4	5
10. I needed to learn a lot of things before I could get going with the system	1	2	3	4	5