



**NTNU – Trondheim**  
Norwegian University of  
Science and Technology

# The Patient Perspective: Utilizing Information Visualization to Present Health Records to Patients

**Håkon Dale Wågbo**

Master of Science in Computer Science

Submission date: June 2014

Supervisor: Rune Sætre, IDI

Co-supervisor: Øystein Nytrø, IDI

Norwegian University of Science and Technology  
Department of Computer and Information Science



# Abstract

Electronic health records (EHRs) are being adopted into healthcare. At the same time patients has begun to take greater interest in their own health and personal health records (PHRs) are increasingly gaining attention.

This thesis explores:

- (1) The patients' perspectives towards gaining access to their EHR data through a PHR system, and how these perspectives affect health record visualization,
- (2) if patients benefit from information visualization when presented with health records,
- (3) and if it is feasible to utilize information visualization techniques derived from state-of-the-art EHR visualization to present health data to patients.

During this project, an online questionnaire was conducted, a case study investigating functional appropriateness and usability was executed, and a feasibility analysis of genuine usage was performed.

The results suggests that patients are very interested in gaining online access to their health records, that they want extensive insight to their EHR data, and that they are very open to the idea of sharing any information they were to supplement the health record with. Many of the visualizations techniques developed for practitioners seems to be transferable to patients. Utilizing information visualization when presenting health records to patients seems to be more functional appropriate than presenting them in a text-based tabular format. In addition, the results indicate that it is feasible to present health events as an interactive timeline to patients.

# Sammendrag

Elektroniske pasientjournaler (EPJ-er) er på vei inn i helsevesenet. Samtidig har pasienter begynt å ta større ansvar for egen helse og personlige pasientjournaler (PHRs) får stadig økende oppmerksomhet.

Denne masteroppgaven utforsker:

- (1) Pasientenes synspunkter på å få tilgang til sine EPJ-data gjennom et PHR-system, og hvordan disse perspektivene påvirker helsejournalvisualisering,
- (2) om pasienter drar nytte av informasjon visualisering når de blir presentert pasientjournaler,
- (3) og om det er gjennomførbart å utnytte visualiseringsteknikker fra moderne EPJ-visualisering for å presentere helsedata til pasienter.

I løpet av dette prosjektet, ble en spørreundersøkelse på nett gjennomført, en brukerundersøkelse som utforsket funksjonell hensiktsmessighet og brukbarhet ble utført, og en gjennomførbarhetsanalyse av genuin bruk ble gjort.

Resultatene tyder på at pasientene er svært interessert i å få tilgang til sine journaler på nett, at de vil ha omfattende innsikt til sine EPJ-data, og at de er svært åpne for ideen om å dele informasjon de eventuelt skulle supplere journalen med. Mange av de visualiseringsteknikkene som er utviklet for leger ser ut til å være overførbare til pasienter. Det å utnytte informasjon visualisering når pasientjournaler presenteres til pasienter, synes å være mer funksjonelt hensiktsmessig enn å presentere dem i et tekstbasert tabellformat. I tillegg indikerer resultatene at det er gjennomførbart å presentere helsedata i en interaktiv tidslinje til pasienter.

# Preface

This master thesis has been written in affiliation to my degree in computer science at the Norwegian University of Science and Technology. It was written in collaboration with the PAsTAs project, and is a continuation of the work that was done in a preliminary project that was carried out in the fall of 2013.

I would like to thank Rune Sætre and Øystein Nytrø for their guidance, and Terje Røsand for his support regarding the case study. I would also like to thank Aslak Steinsbekk, Per Schrader, Gro Berntsen and Eivind Dale for their remarks and input. All the support I have received from friends and family has also been greatly appreciated.

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# Acronyms and abbreviations

**EHR** – Electronic Health Record

**EPHS** – Epicurus Personal Health System

**EPHVis** – Epicurus Personal Health Visualization

**HMU** – Helsenorge Mash Up

**HTML** – HyperText Markup Language

**JSF** – JavaServer Faces

**NSD** – Norwegian Social Science Data Services

**NST** – Norwegian Centre of Integrated Care and Telemedicine

**NTNU** – Norwegian University of Science and Technology

**OWL** – Web Ontology Language

**PAsTAs** – Patient’s Trajectories

**PATH** – Patient Pathways in Cancer Care

**PHR** – Personal Health Record

**RDF** – Resource Description Framework

**RDFS** – RDF Schema

**REK** – Regional Committees for Medical and Health Research Ethics

**URI** – Uniform Resource Identifier

**URL** – Uniform Resource Locator

**URN** – Uniform Resource Name

**W3C** – World Wide Web Consortium

# 1 Introduction

As technology advances, so does computer science's influence on healthcare. Patient data are increasingly being stored digitally, and many health care organizations have adopted electronic health records (EHRs) to replace the paper-format health record.

Although EHRs has become increasingly popular the past decade, most of the systems that have emerged are text-based abstractions of the paper-format health record that utilize few information visualization techniques beyond simple charts. However, some efforts have been made to create visualizations that exploit human cognition to help practitioners make sense of large amounts of health data. Research on EHR visualization suggests that utilizing dynamic timelines to present health events may help the practitioner to make sense of complex health data (Rind, et al., 2011).

Another type of health system that has retrieved increased attention, especially from patients, are personal health records (PHRs) (Tulu, et al., 2012; Rind, et al., 2011). In these systems, the health information is often added and maintained by the patient themselves, however some vendors provides interconnectivity with health care organizations' EHR systems. Similar to most EHRs, PHR systems does not commonly utilize information visualization techniques beyond simple charts (Fernández-Alemán, Llor, Ouhbi, Toval, & Carrión, 2012; Faisal, Blandford, & Potts, 2012).

As Faisal et al. describes it as the following:

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*[.] PHRs are largely text based and provide little support for sensemaking. It remains an open research question as to whether richer ways of managing personal health information, which better support sensemaking, will enhance patient engagement in health decision-making, particularly for those with long-term conditions. (Faisal, Blandford, & Potts, 2012)*

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Considering that many patients have begun to take direct responsibility over their own health records (Constantinescu, Kim, & Feng, 2009), and that the adaption of electronic health records facilitates distribution of EHR data to the patients themselves, this project aims to investigate patients' attitude and perspectives towards getting online access to their EHRs.

Additionally, advances in web-technology has rendered it possible to create advanced information visualization user interfaces that could simplify the process of understanding the potentially complex patient data. Thus, this project

also aims to investigate how EHR visualization techniques that has been developed for practitioners translate to presenting EHR data to patients, their perspectives, and if patients could benefit from information visualization.

## 1.1 Report outline

This chapter gives a description of the content and purpose of each individual chapter in the report.

### **Chapter 2 - Background**

Describes research, technologies and terminology relevant for this paper.

### **Chapter 3 - Problem analysis**

Gives a concise description of the problem investigated in this paper and the motivation behind it.

### **Chapter 4 - State-of-the-art**

Describes state-of-the-art health record visualization to patients.

### **Chapter 5 - Methods**

Describes the methods utilized in this project.

### **Chapter 6 - Implementation**

Gives an insight to the implementation of the applications that were tested.

### **Chapter 7 - Results**

States the results of the research.

### **Chapter 8 - Discussion**

Discusses the findings and assess their credibility and limitations.

### **Chapter 9 - Conclusion**

States the conclusion of this project.

### **Chapter 10 - Future works**

Gives some recommendations to future works and research.

## 2 Background

This chapter provides an explanation of the main research, technology and terms relevant to this project. First, the PAsTAs project is introduced. Then electronic health records and personal health records are described. Thereafter, an introduction to information visualization and Semantic Web is given.

### 2.1 The PAsTAs project

The PAsTAs project is a cooperation between the Norwegian Centre of Integrated Care and Telemedicine (NST) and the Norwegian University of Science and Technology (NTNU). The objective of the project is to:

- 1) Develop methods to examine patient trajectories in primary health care from data exported from EHRs.
- 2) Examine the impact of patient trajectories in relation to the use of specialist health services and the patient's evaluation of the services they have received.

Part of the PAsTAs project is to conduct a large-scale survey which demands sharing patient data with the patients themselves. The preliminary project of this thesis was initiated to investigate methodology for presenting health information to patients and to start the development of a web questionnaire application which could utilize such techniques (Wågbo, 2013).

### 2.2 Electronic health records

KITH, the Norwegian Centre for Informatics in Health and Social Care, defines electronic health record (EHR) from the Norwegian law of health professionals and the regulations on health records as the following<sup>1</sup>:

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*An electronic health record is an electronically kept collection or compilation of recorded/registered information about a patient in connection to health care.*

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<sup>1</sup> Translated from KITH's webpage: [http://www.kith.no/templates/kith\\_WebPage\\_\\_\\_569.aspx](http://www.kith.no/templates/kith_WebPage___569.aspx)

An EHR typically contains relevant information about the patient, such as social security number, name, gender, date of birth, and information about the patient's medical history and test results.

EHRs are maintained and used by medical professionals to facilitate effective health care services. Often, these EHRs are made available in health care organizations through distributed information systems, which can be accessed by clinicians.

## 2.3 Personal health records

Weibel et al. (2013) defines PHR as:

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*PHR refers to a repository of personal health information (PHI) to be managed and accessed by a patient and others authorized by the patient.*

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The patients themselves often form and maintain these health records. However, they may also retrieve health information from external systems, such as EHRs. Either way, the main purpose of PHRs is to help patients keep track of their own health.

There are many types of PHRs, spanning from simple paper based and spreadsheet health records to computer systems and online applications. In this report, the term PHR will be used to describe a personal online health record, which primarily retrieves health data from the patients' EHRs.

## 2.4 Information visualization

Spence (2007) uses the dictionary to define:

*Visualize* - "to form a mental model or mental image of something".

In the context of computer science, the research field of information visualization investigates how to enable users to gain a deeper understanding and insight to data, by exploiting human visual perception. This involves using abstract data representations to facilitate human cognition.

As a simple example, periodically measurements, such as stock value, are often visualized as temporal graphs, as illustrated in Figure 2.1 below.

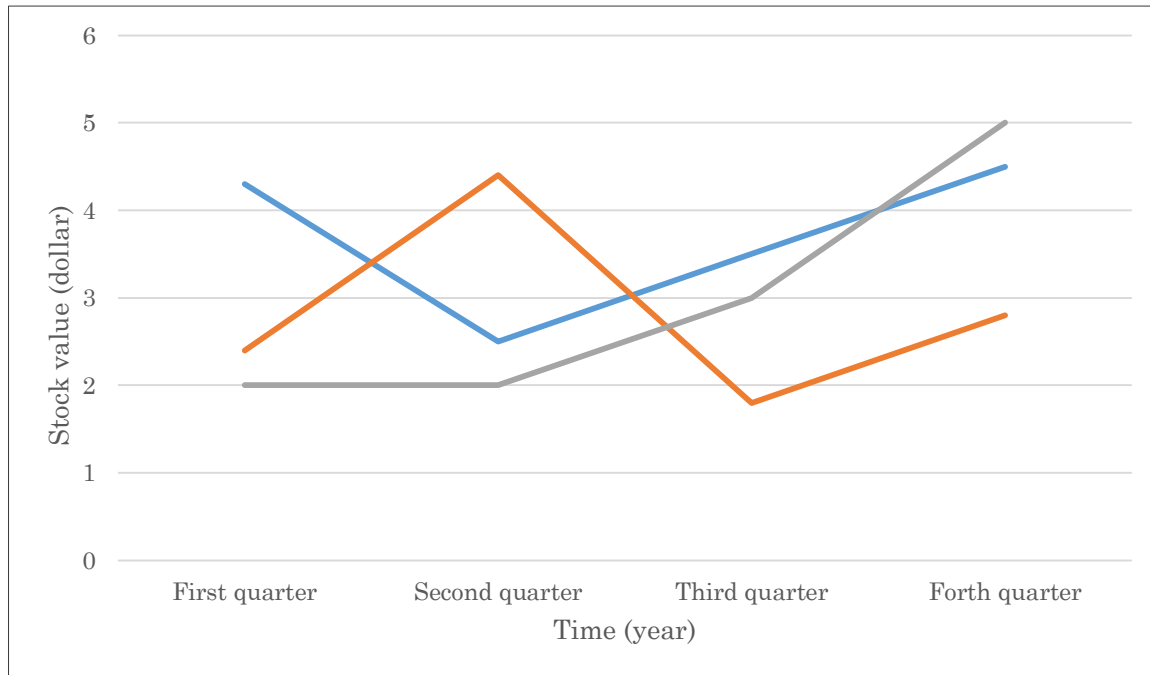


Figure 2.1: Example of information visualization.

The example visualization gives insight to information such as development over time and correlation between stocks. Information, which typically would be harder to analyze for humans if presented purely numerically, especially if there are many values.

Aiger et al. highlight three major criteria that any visualization should aim to fulfill (Aiger, Miksch, Schumann, & Tominski, 2011):

- **Expressiveness** – Showing exactly the data and nothing more, eliminating any visual noise / disturbance.
- **Effectiveness** – the degree to which visualization addresses the cognitive capabilities of the human visual system and context-related information, to obtain intuitively recognizable and interpretable visual representations.
- **Appropriateness** – A cost-value ratio in order to assess the benefit of the visualization process with respect to achieve a given task.

In this aspect, they highlight two questions that needs to be answered when designing visualization: “What has to be presented?” and “Why does it have to be presented?”

Schneiderman often describes a mantra as the basic principles to follow when designing information visualization solutions (Schneiderman, 1996; Schneiderman, Plaisant, & Hesse, 2013):

- Overview first, zoom and filter, then details-on-demand.

This mantra suggests that the user is first presented with the entire collection of data to gain overview, than the user can zoom in on items of interest and/or filter

out uninteresting items. Finally, the user can select an item, or a group of items, and get details as needed.

There are countless different visualization techniques, each appropriate for a bounded area of use. The information visualization techniques utilized in this project was mapped by a state-of-the-art assessment, which is described in greater detail in chapter 4.

## 2.5 Semantic web

Semantic Web was not introduced in the introduction, but was relevant for this project in the implementation in order to cope with the sparse and heterogeneous nature of health data; this is further described in section 5.1.2 in the method chapter. This section gives an introductory explanation of the Semantic Web<sup>2</sup>.

In traditional Web, representations of data are shared across the Internet. This is accomplished by exchanging Web pages written in the HyperText Markup Language (HTML) where data is embedded into the way the data is presented. Although there are some techniques that may enable the end-user to abstract data from the presentation, there is not standardized way of doing this and it may be very troublesome if the data provider does not facilitate for such abstraction.

The purpose of Semantic Web is to enable a distributed web of data where the semantics (i.e. the meaning) of the data are maintained. The foundation of Semantic Web is an “Open World Assumption”. This means that there are no assumptions of the existence of data, and that there are no assumptions of which data that may exist. In other words, there are no limits what data that may or may not exist about something. This makes Semantic Web very suitable for handling heterogeneous and sparse data.

### 2.5.1 Ontologies

When discussing Semantic Web, the term ontology frequently comes up. The term originates from philosophy and describes the study of the existence of things, the taxonomy of existing things and the relationship between them. In the context of Semantic Web, the term has a quite different meaning, and there are many different definitions of the term.

Hitzler et al. defines ontology in computer science the following:

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<sup>2</sup> Parts of this explanation is derived from the report of the preliminary project (Wågbo, 2013).

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*An ontology is a description of knowledge about a domain of interest, the core of which is a machine-processable specification with a formally defined meaning.* (Hitzler, Krötzsch, & Rudolph, 2010)

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Allmang & Hendler simply referes to ontologies as “semantic models”.

In this report, ontology will mean “machine-processable semantic models, which are written in accordance to formal representation languages”.

## 2.5.2 Representation languages

There exists several different representation languages for the Semantic Web. These languages are designed to model expressive knowledge and to access implicit knowledge by logical inference. This section will describe three well-established languages: Resource Description Framework (RDF)<sup>3</sup>, RDF Schema (RDFS)<sup>4</sup> and OWL 2 Web Ontology Language (OWL)<sup>5</sup>. These three languages are standardized by the World Wide Web Consortium (W3C) and are all on W3C’s recommendation list.

### 2.5.2.1 RDF(S)

RDF is often used as a foundation for the Semantic Web and is therefore described first in this section.

#### 2.5.2.1.1 *Modelling with directed graphs*

RDF is based on directed graphs, which consists of a set of nodes that can be interlinked by directed edges. In RDF, the directed graphs are used to model the objects of interest and the relationship between them. The nodes represent the objects and the edges describes the relationships between them.

One of the main arguments for using directed graphs in RDF is that the graphs can easily be merged together without creating duplications, and at the same time maintain the relationships between nodes. Furthermore, since graphs do not need to be complete, unrelated graphs can be merged together.

#### 2.5.2.1.2 *Resources, properties, literals*

In RDF the objects are often referred to as “resources”, hence the name Resource Description Framework. Resources are things that are found in the “real world”. Contrary to many other modeling languages, RDF do not try to encapsulate objects, but simply refers to them. This way, models are related to the actual objects themselves, and hence preserves semantics. In addition to these

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<sup>3</sup> <http://www.w3.org/RDF/>

<sup>4</sup> <http://www.w3.org/2001/sw/wiki/RDFS>

<sup>5</sup> <http://www.w3.org/2001/sw/wiki/OWL>



references to real world objects, the RDF provides literals. These are used to describe values, and are arbitrary strings, composed by characters, digits or both<sup>6</sup>. These may only exist when connected to an object.

The relationships between these resources, i.e. the edges, are often called properties. The direction of the edge describes which node that possesses the property. E.g. if a resource *A* has an edge directed towards another resource *B*, then resource *A* has the property described by the edge to resource *B*. Note that the edge does not describe resource *B*'s relationship to resource *A*.

An example of an RDF model is given in Figure 2.2, here the oblong circles are the references to “real world” objects and the square is a literal. These constitutes the nodes in the directed graph. The directed edges describes the relationship from one node to another.

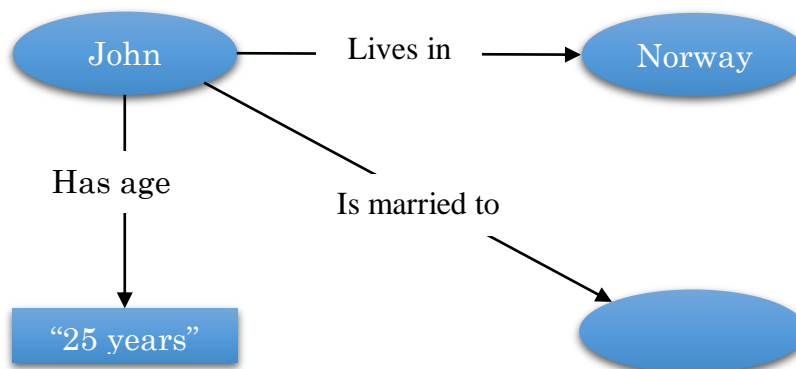


Figure 2.2: Example of directed graph.

In this example, we can establish from the graph that John has an age of 25 years, that he lives in Norway and that he is married. The resource that does not contain a textual description is a so-called blank node. This is a special case node that is used to simply show that a resource exists, but it is unknown what this resource is. This enables modeling such things as in the example: John is married to someone, but it is unknown whom.

Because of all this, RDF has very high modularity, but at the same time is very flexible towards sharing knowledge between systems and deduction of new knowledge by merging data (i.e. graphs). This is also one of the main goals of Semantic Web (Allemang & Hendler, 2011).

### 2.5.2.1.3 Triples

Graphs are very convenient when modelling, but they are not particularly practical for sending data over networks or being processed by computers. It is

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<sup>6</sup> Literals be associated with data types which restricts which characters/numbers it can contain.

therefore desirable to serialize the graphs, i.e. describing them as textual strings. In RDF, the fundamental building blocks of directed graphs have been abstracted into something called triples. A triple contains a subject, a predicate and an object, in that order. A predicate represents a directed edge, and describes a relationship the subject has to the object. The subject and object represents resources. Contrary to the object, the subject cannot be a literal. This is because “values” does not have properties.

Looking back at the example above, “John lives in Norway” could be converted to a triple where “John” is the subject, “livesIn” is the predicate and “Norway” is the object<sup>7</sup>.

#### **2.5.2.1.4 URIs**

In order to be able to identify the abstract things that cannot themselves be interpreted by computers (e.g. people, countries, planets) resources and properties are named with Uniform Resource Identifiers (URIs)<sup>8</sup>.

URIs are names that identify resources on the Web. The more commonly known URLs (Uniform Resource Locators) are examples of URIs. However, URIs may also be Uniform Resource Names (URNs) that does not need to be available on the Web to be valid. Therefore, ontologies may use any URI, but since ontologies can be merged, it is desirable to have ownership of the URIs that is used. If not, merging ontologies may cause ambiguities in the data.

Prefixes are often used to represent the first part of the URIs as they are often the same. For example, “http://www.w3.org/1999/02/22-rdf-syntax-ns#type” can be written as “rdf:type”. The prefix “rdf” is then equivalent to writing everything before the hash symbol in the URI.

#### **2.5.2.1.5 Classes and individuals**

RDF distinguishes resources that are classes and resources that are individuals. A class describes a group of things, while an individual is a thing that can be an instance of a class. For example, the class “country” describes the group of individuals that are countries. “Norway” is an example of an individual that instantiate this class. The fact that “Norway” is part of the class “country” is another example of a property.

In this document, the typical naming convention will be followed where names of classes starts with a capital letter, and properties and individuals starts with a lowercase letter.

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<sup>7</sup> The predicate is named in one word to emphasize that this is an atomic unit.

<sup>8</sup> Literals does not need to be named with URIs as they represent values that are interpretable by computers.

### **2.5.2.1.6 RDF Vocabulary**

RDF also comes with a little vocabulary, which contains a set of resources with specifically defined semantics. This vocabulary contains the class `rdf:Property` that can be used to explicitly describe that a resource is a property. This is convenient as it is sometimes vague which resources that represents objects and which that represents properties. The vocabulary also contains the property `rdf:type` that can be used to describe which classes an individual instantiate.

In addition to these and some other resources, the vocabulary contains a set of axioms. An axiom is an assertion that is considered true without controversy. For example, `Rdf:type` is an property and is therefore an instance of the class `rdf:Property`. Hence, the vocabulary contains the axiom “`rdf:type rdf:type rdf:Property`”.

### **2.5.2.1.7 RDF Schema**

RDF Schema (RDFS) is an extension of RDF. This extension is simply a RDF vocabulary that is put on top of RDF to enrich it. Amongst other things, RDFS extends RDF by providing ways to model:

- class hierarchies (`rdfs:Class` and `rdfs:subClassOf`)
- hierarchies of properties (`rdfs:subPropertyOf`)
- restrictions on which resources that may have a certain property (`rdfs:domain`)
- restrictions on what a property can point to (`rdfs:range`)
- which resources that are data types (`rdfs:Datatype`), literals (`rdfs:Literal`) and resources (`rdfs:Resource`)

## **2.5.2.2 OWL 2**

The OWL 2 Web Ontology Language is an extension and revision of the OWL Web Ontology Language. Although this section will describe OWL 2, most of it is also applicable to OWL 1 and OWL 1.1. Regardless, the term OWL will be used for the rest of this paper to mean OWL 2.

OWL is a representation language for creating Semantic Web ontologies that was designed to a greater extent facilitate for expressing meaning and semantics than RDF and RDFS. Thus, OWL goes beyond these languages in its ability to represent machine interpretable content on the Web (W3C, 2004).

### **2.5.2.2.1 The semantic layer: OWL Full and OWL DL**

A central goal in OWL, is to provide a reasonable balance between the expressiveness of the language, and how effective it is to reason with the language. As this balance can be hard to establish, a semantic layer is introduced to the language. This layer contains a vocabulary that is used to interpret ontologies. Consequently, this vocabulary determines the expressiveness and semantics of the language. The most expressive version is

OWL Full, which contains the whole language without restrictions. In OWL Full, the OWL language constructs can be mixed freely with all RDF(S) language constructs. This means that all RDF(S) ontologies, are also valid in OWL Full. However, there are some problems with OWL Full that makes it impractical in many situations. Because of the extensive expressiveness of OWL Full, drawing inferences are generally undecidable (Hitzler, Krötzsch, & Rudolph, 2010). Therefore, the more restrictive version called OWL DL is commonly used. OWL DL is a syntactically restriction of OWL Full. However due to these restrictions, it is possible to always draw inferences that are decidable, i.e. either true or false.

#### ***2.5.2.2.2 Classes, individuals, abstract roles and concrete roles***

Just like in RDF, the building blocks of OWL ontologies are classes, properties, individuals and literals. Properties in OWL are commonly referred to as “roles”, and this report will use this term from this point onwards. Nevertheless, roles and properties are synonyms for the same entity.

Classes in OWL are resources that represents groups with certain commonalities and are declared with the identifier `owl:Class`.

Roles are resources that represent properties or relationships. In OWL, roles are divided into two different types: abstract roles and concrete roles. Abstract roles connects resources to resources, while concrete roles connects resources to literals. Abstract roles are declared with the identifier `owl:ObjectProperty`, while concrete roles are declared with `owl:DataProperty`.

Individuals represents resources that are instances of classes. Individuals are declared with the identifier `owl:Individual`.

#### ***2.5.2.2.3 The syntax layer: RDF/XML and Manchester syntax***

In addition to the semantic layer, OWL implements a syntax layer. Syntaxes are formal ways of expressing ontologies in OWL that are readable for computers. By introducing the syntax layer, it is possible to write OWL ontologies in different syntaxes. The only requirement for an OWL ontology is that it can be expressed in the RDF/XML syntax. The RDF/XML syntax comes from RDF, and uses XML to represent ontologies.

Manchester syntax is an alternative syntax to RDF/XML. Although it sets a small number of restrictions on the expressiveness of OWL, this syntax is designed to facilitate human readability (W3C, 2012).

# 3 Problem analysis

Electronic storage of health data has become more common in healthcare. This makes it possible to provide patients access to these data through the Web. In addition, information visualization has started to make its way in to EHR systems. However, little effort has been made to research and apply similar information visualization techniques to PHRs.

## 3.1 Research demand

Faisal, Blandford, & Potts published in 2012 a systematic literature review on information visualization for making sense of personal health information.

From this review, they identify five application themes: treatment planning, examination of patients' medical records, representation of pedigrees and family history, communication and shared decision making, and life management and health monitoring. These themes were discussed over two dimensions; users and research challenges. They identify three user categories: practitioners, practitioners with patients and patients; and three research categories: data visualization, capturing lifestyle, and goals and tasks. Data visualization concerns finding visual representations to communicate the desired quantitative concepts, capturing lifestyle concerns the data collection, and goals and tasks concerns goals and tasks of users that the visualization tools are supporting and on the complexity of the problem.

The general findings in the review is that:

- 1) Research reviewed on treatment planning is mainly on data visualization, with practitioners as the intended users.
- 2) Research reviewed on examination of patients' medical record emphasizes data visualization and capturing lifestyles, with practitioners as the intended users.
- 3) Research reviewed on pedigrees and family history is mainly on data visualization, with practitioners and patients as intended users.
- 4) Research reviewed on communication and shared decision-making emphasizes data visualization and capturing lifestyles, with practitioners and patients as intended users.
- 5) Research reviewed on life management and health monitoring emphasizes on capturing lifestyles, and goals and tasks, with patients as the intended users.

For this project, representation of pedigrees and family history is not relevant. However, the rest of the findings complies with the overall impression of

research literature reviewed through this project. There is some literature about utilizing information visualization to present health records to practitioners, but no literature that explicitly addresses utilizing information visualization to present health records to patients. Most of the literature that was examined during this project that considered patients as users, focused on management of lifestyle or specific chronic diseases and conditions, with little or no utilization of information visualization (although simple charts were sometimes adopted).

Faisal et al. concludes in their literature review that further research is needed to uncover patients' needs, especially when it comes to making sense of managing and communicating health-related issues (Faisal, Blandford, & Potts, 2012).

Scheiderman et al. published in 2013 an article discussion the role of information visualization in healthcare. In this article they discuss the need for substantial research and development of information visualization in PHRs.

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*Interactive visual presentation that allow drilling down to gain background information, show comparisons and highlight anomalies will improve patients' understanding of their health and medical conditions. Developing these personal health visualizations require considerable research and validation (Schneiderman, Plaisant, & Hesse, 2013).*

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## 3.2 Current situation and solutions in Norway

Norway has yet to develop a standardized EHR. However, something called "kjernejournal" (translates to "core-record") has been developed. This core record contains some information about the patient, such as name, address and emergency contacts, in addition to some general medical data, such as current prescriptions, recent visiting history, vaccines and critical allergies.

In the annual health conference<sup>9</sup> in Norway in 2014, patient centric care was a much-debated topic. The Minister of Health and Care Services, Bent Høie, stated that "the more the patient knows, the better". "More active patients" was also the first thing the Prime Minister, Erna Solberg, highlighted as important things in developing "the patient's health care", together with new technology and exchange of knowledge and experiences (Grotdal, 2014).

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<sup>9</sup> <http://www.helsekonferansen.no/>

### 3.2.1 Personal Health data

Some research has indicated that an informed patient helps facilitate a good path of treatment, and that sharing health information with the patients through PHR systems may help facilitate health preserving (Constantinescu, Kim, & Feng, 2009). The Norwegian federal government have made an effort towards patient-centric health care by making the so-called “core journal” available for patients through a Web interface called “My Health”<sup>10</sup>.

The web interface gives the patients an overview of their health care visits, payments, prescriptions, emergency contacts, allergies and vaccinations. The web interface also allows patients to update their personal information, contact information, drug side effects and critical information that could be useful in case of emergency (e.g. contaminations, allergies and medical conditions).

Due to legal restrictions and the lack of EHR standardization in Norway, these data are limited. However, at the time of writing, an EHR standard is being developed, and government is determined to change the law so that EHRs can be made available for the patients themselves.

## 3.3 Project goal

The overall goal of this project is to investigate the patients’ perspectives and attitudes towards online health records, in addition to how state-of-the-art EHR visualization techniques that have been developed for practitioners translate to presenting health information to patients.

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<sup>10</sup>The web interface can be accessed from <http://helsenorge.no>

## 3.4 Research questions

The research questions that this project aims to investigate is given below:

**RQ 1:** What are patients' perspectives on online access to their health records (i.e. a PHR that provides their EHRs) and how does these perspectives influence the way the health records should be presented?

**RQ1.1:**

Does patients consider it useful to gain online access to their health records?

**RQ1.2:** What use case support does patients consider important in a PHR that provides their EHRs?

**RQ1.3:** What information does the patients think is important to gain insight to about health services they have utilized?

**RQ1.4:**

Would patients consider sharing personally submitted data, and if so, with whom?

**RQ 2:**

Would patients benefit from information visualization when presented with health records?

**RQ 3:**

Is it feasible to utilize information visualization techniques derived from state-of-the-art EHR visualization to present health data to patients?



# 4 State-of-the-art

This chapter describes the current state-of-the-art of online PHRs that utilizes information visualization and provides EHR data.

The state-of-the-art description is a product of a structured literature review that searched for information about:

- What should be visualized?
- How should it be visualized?
- What kind of interactions can help the patient browse their data, and where is the limit for these sorts of interaction (i.e. when does it get to complicated)?
- What other functions should be provided?

The literature review followed a structured plan, as illustrated below.



*Figure 4.1: Literature review structure*

First, the literature was planned. In this step, it was decided what was to be included, what were the conceptual queries and which databases was to be used. Two topics were identified to be relevant for this review: Visualization of singular EHRs and visualization of PHRs. The search limits were peer reviewed journal articles, literature reviews and conference proceedings, in Norwegian or English. No geographical limits were set, however this may have been affected by the language dependency (as some regions do not commonly use English). No time limit was set, but because of the tremendous technological development the past years, the focus was on newer research. The conceptual search was “health record visualization”.

The databases that were searched was IEEE Xplore digital library, Medline/PubMed and ACM Digital Library. In addition, DAIM<sup>11</sup> was searched for relevant articles already conducted on the field at Norwegian universities and colleges.

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<sup>11</sup> Digital Archive and Submissions of master thesis

The second step was the actual search. This was a systematical search implementing the plan in step one. Since the databases utilized Boolean search, this search was done exhaustively. This means that for each search query, all hits were reviewed by title and abstract.

In the third step, the literature that resulted from the search was assessed. Literature found not to be relevant was filtered out, and those found to be relevant was read and summarized. In the last step, a coherent summarization of the findings in the literature was written, resulting in the sections below.

## 4.1 Health record visualization

As mentioned earlier, none of the literature reviewed in this project points to an available solutions that utilize information visualization to present health records to patients. The only visualization that is commonly used in PHRs are charts to view measurements. However, research was found on EHR visualization with practitioners as the target users.

As the usage intent differs in EHR visualizations, it was hard to identify the techniques for visualizing health record that are relevant for this project. Many of the EHR systems that utilizes information visualization beyond simple charts are designed for the purpose of medical analysis of a population or patient group. These systems are not part of this assessment. Neither are visualization techniques that are designed for medical analysis or treatment planning. This project is interested in visualization of singular health records, with the primary intent of browsing.

Two visualization techniques emerged as the most commonly used. The first technique is visualizing health records as a timeline of temporal events. The second common technique is visualizing health records as humanoid avatars, where parts of the body can be abstracted and inspected (Schneiderman, Plaisant, & Hesse, 2013). These structures differs substantially, as the second does not visualize the time dimension. Nevertheless, the emphasis in the research literature is unequivocally focused on the first, visualizing temporal events on a timeline (Rind, et al., 2011) (Rajwan & Kim, 2010) (Faisal, Blandford, & Potts, Making sense of personal health information: Challenges for information visualization, 2012). Thus, this state-of-the-art assessment will do the same.

The most central literature for assessing state-of-the-art health record visualization was *Interactive Information Visualization to Explore and Query Electronic Health Records* (Rind, et al., 2011), *Making sense of personal health information: Challenges for information Visualization* (Faisal, Blandford, & Potts, 2012), *A comparison of several key information visualization systems for secondary use of EHR content* (Roque, Slaughter, & Tkatsenko, 2010), and

*Visualization of Medical Data Based on EHR Standards* (Kopanitsa, Hildebrand, Stausberg, & Englmeier, 2013).

### 4.1.1 Visualization of categorical data

The most common way to visualize categorical data is by event-oriented horizontal timelines. These timelines represent time on the x-axis from left to right, and the temporal representation is usually linear, i.e. each even time unit on the x-axis equals the same amount of time.

Events that taking place at a specific point in time are represented as dots or icons on the timeline, and events that take goes over a period are represented as horizontal rectangles or lines. The events are placed on the timeline according to the time they started. Periodical events (intervals) additionally have horizontal length according to the event's extent in time. These events are usually grouped in lanes by some categorization on the y-axis. The categorization differs, some systems group events by some abstract categorization, such as hospital, medicine, tests, while others group by diagnoses or treatment. Some systems also provide several different categorizations.

In addition, colors are often used to differ between types of events. Some also use shape and size of icons to convey additional information. Rind et al. found no use of distinct visualization for specific types of medical information (diagnosis, treatment, drugs) in the systems they tested used.

### 4.1.2 Visualization of numerical data

In EHRs, the numeric data is typically test results. When presented as pure numerical data, these are usually visualized as line plots. However, point plots and bar charts are also used to some extent.

Most systems can align numerical and categorical data along a shared time axis, and in this way see development over time and compare narrative to numeric values. Different techniques are utilized for doing this. Some use glyph-size and color to represent different numerical values in events. More commonly, line charts are used to show values with events on the same timeline. Although these visualizations often share the same timeline, different numeric values and categorical data (such as diagnoses and treatments) are usually put in separate panels to reduce clutter and accommodate scales and value ranges (Rind, et al., 2011).

In addition, some systems support providing categorical information about numerical values, such as “low/normal/high” or color, to indicate abnormal values.

### 4.1.3 Functions

The functions that are provided in systems that provide health record visualization are diverse, but there are some that often reoccurs.

First, a very commonly supported function is navigation in time. By providing zooming and panning capabilities many system enable abstraction of events in a specific period. Some also provides a semantic zoom, change the detail level of events according to zoom level. The semantic zoom typically cluster related events, or regulate visual/textual detail on each individual item in the timeline. Semantic zoom is however not widely adopted.

Another very common function is on-demand details. Details are usually provided as events on the timeline are clicked, and are presented in a tooltip. However, some provide the details in a separate section of the page, typically besides the timeline. Details are typically textual, but some systems also provide pictorial details, such as MRI imagery.

Filtering is also to some degree supported. As an example LifeLines provide a search function that highlight events that are related to query. However, filtering is not widely adopted in single health record visualizations because of the data size.

## 4.2 PHRs

PHR is a wide term that describes several different systems. Most of them are designed for keeping track of personal health, often in a specific context such as a chronic disease or dieting. PHRs are mostly developed with the idea of patients themselves supplying and maintaining the health information. There are some PHRs that support retrieval of EHR data, however this is usually provided as a supplement. As mentioned earlier, PHRs are mostly text based, but some provide simple charts to present test values or the like. The review of literature performed in this and other projects suggests that there has been very little research on information visualization in PHRs (Faisal, Blandford, & Potts, 2012). However, some research papers highlight considerations that needs to be taken when utilizing information visualization in PHRs. These are summarized in this section.

Most central for this assessment was *Making sense of personal health information: A Comparison of Several Key Information Visualization Systems for Secondary Use of Electronic Health Record Content* (Roque, Slaughter, & Tkatsenko, 2010), *Medical Information Visualization Conceptual Model for Patient-Physician Health Communication* (Rajwan & Kim, 2010), *Challenges for information Visualization* (Faisal, Blandford, & Potts, 2012) and *Interpreter-Mediated physician-Patient communication: opportunities for multimodal healthcare interfaces* (Weibel, et al., 2013).

### 4.2.1 Health illiteracy

Many patients are not educated in or work with health, and may therefore have limited knowledge about health. The visualization in PHRs needs to account for this limitation by providing explanations of medical terms and health data visualizations (e.g. diagrams and figures).

Patients' also need additional support in interpreting the health data. Some examples of such support is by providing indicators or a textual patient-friendly summary.

### 4.2.2 Computer literacy

PHRs are adopted with no, or little, training. Patients is a very heterogeneous group in which computer literacy varies severely. The visualization should to accommodate for this, in that it needs to be easy to use and understand. Patients may have different needs dependent on their overall computer literacy, and the PHRs should provide suitable representations for all these patients.

### **4.2.3 Culture, Internationalization and localization**

The culture and language differs between patients, also within the same countries. The visualization needs to provide multi-language support, and should provide uniform representations that are properly interpreted across different cultures.

### **4.2.4 Disability**

Patients with disabilities constitute some of the users that might have use for PHRs. There are many forms of disabilities, such as patients with impaired eyesight and patients with cognitive deficits. Either the visualization should accommodate for these disabilities, or alternative representations that does should be available if needed.

### **4.2.5 Perspective**

The patients may have different perspectives, which are affected by things such as emotion and subjective experience. These are things that goes beyond the purely medical and factual data. A visualization should strive to account for these perspectives.

# 5 Methods

The methods that have been utilized in this project can be divided into two groups: Implementation methods and research methods.

1. Implementation methods:
  - a. Information visualization
  - b. Semantic Web
  - c. Traditional Web technologies
2. Research methods:
  - a. Online Questionnaire
  - b. Test of functional appropriateness and usability
  - c. Visualization feasibility analysis

In the implementation, three main methods were used. The first, information visualization, are techniques derived from research on state-of-the-art health record visualization. The second, Semantic Web, is technology included in order to create an agile interface to the system that can handle the heterogeneous nature of health data. The third, traditional Web technologies, was used to make the health records available through an ordinary Web browser. These methods are described in section 5.1.

As for the research methods, one survey, one feasibility analysis and one case study were used in this project, each of which has their own section in this chapter. The survey was an online questionnaire that was used to do a quantitative and qualitative investigation of the patients' perspective on online access to their health records. The survey is described in section 5.2.

The case study was user tests on two PHR prototypes that retrieves health data from EHRs. One of these prototypes utilized state-of-the-art EHR visualization, and one used a tabular presentation similar to the current solution in the "My Health" service at Helsenorge.no. This case study was a qualitative investigation of the functional appropriateness and usability of utilizing information visualization when presenting health records to patients, compared with a text-based tabular representation. The case study is described in section 5.3.

The feasibility analysis was an assessment of large-scale usage of state-of-the-art EHR visualization techniques to present health data to patients. The large-scale usage is affiliated with the PAsTAs project, which is currently conducting a survey that provides the participants with a visualization of the healthcare services they have used. The analysis was a qualitative investigation of the feasibility of this visualization and is described in section 5.4.

## 5.1 Implementation

As mentioned, there was found no implementations of a Web PHR that utilizes information visualization techniques derived from state-of-the-art EHR visualization. Therefore, some prototypes were developed as part of this project. This section describes the methods and technologies that were used in the implementation. Chapter 6 gives further insight to the implementation itself.

### 5.1.1 Information visualization

Part of the goal in this project is to assess the feasibility, functional appropriateness and usability of information visualization techniques of temporal health data, derived from state-of-the-art EHR visualization. Hence, the implementation utilizes such techniques.

### 5.1.2 Semantic Web

To cope with the heterogeneous, sparse and ever-changing nature of health data, Semantic Web technology was utilized as an implementation independent foundation for visualization of temporal data. There are also implications that the most efficient development method for health record visualization is a higher-level visual model based on data exchange standards (Kopanitsa, Hildebrand, Stausberg, & Englmeier, 2013).

As mentioned in the background chapter, ontologies are representations of actual objects and properties. In the case of this project, the scope is visualization of health data. This is what the ontology is to represent. Hence, the ontology is not representations of the underlying health data, but rather representations of the visual elements. This is convenient as the semantics of visual elements are far less complex than the semantics of health data.

The ontology was written in OWL 2 DL, in Manchester syntax.

### 5.1.3 Traditional Web technologies and frameworks

As a premise for these applications is that they would be available through the Web, traditional web technologies were utilized to create user interfaces suited for ordinary Web browsers. The web applications were developed in Java, with the frameworks JavaServer Faces (JSF) and Primefaces<sup>12</sup> at its core. Parts of the client side interfaces were additionally developed in native HTML5 and

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<sup>12</sup> <http://www.primefaces.com>



JavaScript. The frameworks JQuery<sup>13</sup>, CHAP Links Timeline<sup>14</sup>, QTip2<sup>15</sup> were also used in this context. For reasoning with the OWL ontologies the OWL API<sup>16</sup> was used. Additionally, as the EPHS provides search functionality, this application implements the Apache Lucene<sup>17</sup> search engine.

## 5.1.4 Equipment

This section quickly summarizes the key equipment that was used during the development and the deployment of the applications.

### 5.1.4.1 Development

During the development two utilities were primary used: NetBeans 8.0 and Protégé 4. NetBeans is an integrated development environment (IDE) which was used to program and test the applications. Protégé is an application that allows the user to browse and create OWL ontologies in a graphical interface.

### 5.1.4.2 Deployment

All applications were deployed on servers running Ubuntu 12.04 LTS, on an Apache Tomcat 7 web server, with OpenJDK 7 running the underlying java virtual machine.

## 5.2 Online Questionnaire

This section describes the online questionnaire survey conducted in this project. Summarized, this survey assess the patients' perspective and attitude towards online access to EHR data, i.e. getting access to a PHR Web application that provides EHR data. The participants were recruited through a random distribution of flyers in several different residential areas in Trondheim. The questions in the questionnaire can be found in Appendix B, and screenshots of the questionnaire can be found in Appendix C.

### 5.2.1 Goal

The goals of this survey are fourfold. The first goal is to investigate if patients consider it beneficial to gain insight to their EHR data.

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<sup>13</sup> <http://jquery.com>

<sup>14</sup> <http://almende.github.io/chap-links-library/timeline.html>

<sup>15</sup> <http://qtip2.com>

<sup>16</sup> <http://owlapi.sourceforge.net>

<sup>17</sup> <http://lucene.apache.org>

Information visualization techniques on EHR data has primarily been developed with regards to the needs of practitioners. Part of this project is to investigate how patients as users influence the requirements of these information visualization techniques. Therefore, the second goal of the survey is to investigate what the patients would use the system for and the patients' perspective on EHR data.

One of the benefits of sharing EHR data with patients for healthcare is feedback, and therefore the third goal is to investigate whether patients would consider sharing any health information the patients were to add themselves.

The fourth goal is to do qualitative data collection of any unforeseen considerations patients may have.

## 5.2.2 Hypotheses

This section describes the hypotheses for the survey. These were based on the findings in the state-of-the-art review, and the preliminary qualitative research on cancer patients' requirements to a PHR application that utilize information visualization done in affiliation with the PAsTAs project (Wågbo, 2013).

- H1) Patients considers it useful to gain insight to their own health record through a web interface.
  
- H2) Patients considers it important to be able to use a system providing them with their health record to:
  - a. Find information about their diagnoses / conditions / illnesses.
  - b. Find information about their treatments and/or medications.
  - c. View health history / help remembering what has happened.
  - d. Keep themselves informed about which data the health service have about them.
  - e. Add their own information / write comments.
  - f. Plan / look up future appointments and events.
  - g. Look up test results.
  - h. Search for / preview information about specific events or health services.
  - i. Give feedback to healthcare about their experiences / their perspective
  
- H3) Patients considers it important to have the following information presented about health services they have utilized:
  - a. Calendar time / date / period
  - b. Place of event / address / building
  - c. Service provider (e.g. St. Olavs Hospital)
  - d. Type of service provider (e.g. hospital, GP)

- e. Type of service (e.g. radiology, blood sample, GP visit).
- f. Name of the clinician(s) that performed or are responsible for the service
- g. Diagnosis / symptoms / illnesses
- h. Procedure performed
- i. Treatment / medication
- j. Values on measurements
- k. Diagnostic images / images taken
- l. Prognosis / probable outcome of condition

H4) Patients would like the opportunity to share their supplement data with researchers and clinicians.

### 5.2.3 Survey design

As mentioned, this survey is both quantitative and qualitative. To assess the hypotheses, quantitative data was collected. It is uncertain if the given set of given set of answer options is complete, thus qualitative data was in addition collected on a voluntary basis from participants.

#### 5.2.3.1 Quantitative data

Quantitative data was collected through multiple-choice questions with a discrete number of answer options was used in order to get a quantitative answer. When possible and suitable, the questions asked the participants to give a rating on a scale from one to six, where one was very low and six very high. This was used as much as possible since it gives a numeric value that is easy to assess by average and median ratings. The maximum rating was even numbered to get the participants to make a decision, and not take a natural position. Although some participants may be indifferent to some things, this questionnaire asked for importance of use cases and health event information. Hence, indifference ought to produce low ratings, not an intermediate neutral value. On questions in which indifference causes a neutral position, or a neutral position was natural, rating was not used and a neutral answer option was provided.

#### 5.2.3.2 Qualitative data

The answer options may not reflect all considerations that the patients' have towards desired use cases and health event information. Since the overall goal of the survey was to assess the patients' perspective, it was important that the questionnaire collected any considerations that had been omitted in the given set of answer options.

The qualitative data collection was done through three optional text fields, one concerning desired use cases, one concerning desired health event information and one for other things and feedback on the survey.

### **5.2.3.3 Questionnaire layout**

The questionnaire was divided into nine logical segments, each of which had their own specific purpose. The logical sections are given below in order of appearance. A complete list of questions can be found in Appendix B.

#### ***5.2.3.3.1 General personal background***

This segment of questions mapped the general personal background about the participant. The information collected was age, gender, level of education and their main activity (i.e. if they were retired, studying, self-employed or working, job seeking, stay-at-home or on welfare).

#### ***5.2.3.3.2 Personal health and health care affiliation***

This segment of questions mapped the participant's health, and if they had professional affiliation with healthcare. Participants' health were established by asking how many times they used healthcare services, if they had received chronic diagnoses, and a self-perceived rating of their own health. Professional affiliation with healthcare was established with a single question if they worked with or had education affiliated with health.

#### ***5.2.3.3.3 Computer skills***

This segment identified the participants' computer skill level. Three elements established this: Self-perceived computer skill level, which gives a sense of how confident participants are about their abilities; how often they use the Internet, to reflect their frequency of use; and lastly, how many different websites they usually used in a week, which indicates how broad their use is.

#### ***5.2.3.3.4 Desire of online access to health record***

This segment investigated if the participants thought it would be useful for them to gain online access to their health record. In addition to establishing quantitative data on the question to answer survey hypothesis H1, this was of important in order to establish credibility of the subsequent segments. If participants did not think such a service would be useful for them, their perspective on such a Web site is nonessential.

#### ***5.2.3.3.5 Importance of use cases***

This segment investigated how important the participants thought a given set of use cases were. This given set of use cases correspond to the list in survey hypothesis H2. They were asked to rate the importance of each use case on a scale from 1 to 6, where 1 was "not important at all" and 6 were "very important". After this, a commentary field was included to pick up other use cases that the participants felt were not represented in the given list.

#### ***5.2.3.3.6 Importance of health event information***

The segment mapped the participants' perspective on the importance of information provided about health events. As in the previous segment, the participants were given a set of different types of information and were asked to rate how important it was for them that the information was provided in health events. The given set of different types of information correspond to the list in survey hypothesis H3.

#### ***5.2.3.3.7 Supplementing and sharing of data***

This segment investigated how open people are to the idea of sharing their own supplemented information to researchers and/or clinicians. It held one multiple-choice question where the participants could choose from the option of sharing everything with both groups, sharing with only one group, sharing only with GP, deciding in each case whom to share with, not sharing with anyone and a neutral answer option for those who didn't know. Hence, the segment yielded a quantitative answer to survey hypothesis H4.

#### ***5.2.3.3.8 Survey comments and competition***

This segment collected any commentary participants had to the survey or the idea of online access to their health record. In addition, participants could supply their phone number if they wanted to partake in a competition. This was saved in a separate store in a way that disabled it from being linked to answer submissions.

### **5.2.4 Recruitment of participants**

Participants were invited through flyers, randomly distributed to most residential areas in Trondheim. Since the target audience is Norwegians who knows how to use a computer, there were no other criteria for participation than that they were able to participate in the online questionnaire and that they understood Norwegian. In order to entice people to participate and inhibit bias, an optional competition was included and advertised in the recruitment process.

As the sample was restricted to the population in Trondheim, estimations of population proportions and mean is also restricted to this area. Note that the term "population" will be used to mean the population in Trondheim from this point onwards in the report.

### **5.2.5 Data analysis**

This section describes the methods that were used during the data analysis of the online questionnaire submissions.

### 5.2.5.1 Estimation of population proportion and mean

To estimate the actual opinion in the general population from the sample that was surveyed through this questionnaire, interval estimates of population proportion and mean was used. The confidence level was set to 95%.

The estimations used are dependent on random sampling and a fixed number of independent trails. The sampling is assumed to be random, however since participation was voluntary, there is no way to be absolute sure about this. This issue is discussed further in section 8.1.1. The fixed number of independent trails were the participants, who answered individually and independently from each other.

#### 5.2.5.1.1 Estimation of population proportion

First, the margin of error,  $E$ , was calculated by:

$$E = z_{\alpha/2} \sqrt{\frac{\hat{p}(1 - \hat{p})}{n}} = 1.96 \sqrt{\frac{\hat{p}(1 - \hat{p})}{n}}$$

Where the standard normal distribution,  $z_{\alpha/2}$ , was 1.96 due to the 95% confidence level, and the observed proportion  $\hat{p}$ , was found by dividing the number of people the sample that possessed the characteristic of interest (i.e. submitted some specific answer option) by the sample size,  $n$ .

Then the 95% confidence interval,  $CI$ , was calculated to estimate the population proportion:

$$CI = \hat{p} \pm E$$

In addition to the dependencies described earlier, this estimation depend on two types of outcomes: success and failure, and at least 5 successes and 5 failures. The estimations were done on specific answer options. Thus, there was two outcomes: the participants answered with the answer option, or they did not. The dependency of 5 successes and 5 failures was assessed in each case.

#### 5.2.5.1.2 Estimation of population mean

First, the sample mean,  $\bar{x}$ , was calculated by summing all sample values and dividing by the sample size,  $n$ .

$$\bar{x} = \frac{\sum_{i=1}^n x_i}{n}$$

Then the margin of error,  $E$ , was calculated by:

$$E = z_{\alpha/2} \frac{s}{\sqrt{n}}$$

Where  $s$  was the standard deviation of the sample, and the standard normal distribution,  $z_{\alpha/2}$ , was 1.96 due to the 95% confidence level.

Then the population mean was estimated by calculating the 95% confidence interval,  $CI$ :

$$CI = \bar{x} \pm E$$

### **5.2.5.2 Acceptance of hypotheses**

Each hypothesis was given a null hypothesis. For hypotheses to be accepted, the lower bound of the estimated population proportion/mean must be higher than a corresponding null hypothesis.

#### **5.2.5.2.1 Acceptance of H1**

H1 states that patients considers it useful to gain insight to their own health record through a web interface. For this to be true, the majority, i.e. at least 50%, of the population must consider it useful. Thus, the null hypothesis is that the estimated population proportion that considers it useful is 50%.

#### **5.2.5.2.2 Acceptance of H2**

H2 states that the given set of use cases are important for patients. A use case is considered important if its rating is above half of the scale, i.e. four or above. Thus, the null hypothesis for each use case is that the estimated population mean of the use case is just under four.

#### **5.2.5.2.3 Acceptance of H3**

H3 states that the given set of types of information for health events are important for patients. A type of information for health events is considered important if its rating is above half of the scale, i.e. four or above. Thus, the null hypothesis for each type of information for health events is that the estimated population mean of the information is just under four.

#### **5.2.5.2.4 Acceptance of H4**

H4 states that the patients would consider sharing the information they supplement to their health record with researchers and clinicians. For this to be true, the majority, i.e. at least 50%, of the population must consider it useful. Thus, the null hypothesis is that the estimated population proportion that considers it useful is 50%.

## **5.2.6 Equipment**

The online questionnaire was a self-developed JSF application called SurveyMaster. The application uses OWL ontologies to produce Web interfaces of questionnaires in a generic fashion. A main ontology describes the classes and roles. To make a questionnaire one simply creates individuals of these classes and input them to the application. These individuals are then parsed by the application, which produce a suitable Web interface with the questions and steps. When participants respond to questions in the Web interface, OWL

individuals are produced that refers to the answer option they answered with and questions that were answered. This application is quite similar to the application that is used in the PAsTAs project, which is a tailored version of SurveyMaster in their survey.

The application was deployed to an Ubuntu 12.04 LTS server. The JSF application was run in runs in an OpenJDK 7 Java virtual machine by Apache Tomcat 7.

After the data collection was complete, another self-developed application was used, called SurveyAnalyzer. This application converted the submissions, which originally were in OWL, into Microsoft Excel file format (XLS). This was done to ease the analysis work. Microsoft Excel 2013 was used for the data analysis.

## 5.3 Test of functional appropriateness and usability

This case study was based on the book *Praktisk Brukertestning*<sup>18</sup> (Toftøy-Andersen & Wold, 2011), consultation with supervisors, the master thesis *Exploring User Interfaces for Search and Content Based Clinical Decision Support in Electronic Health Record Systems* (Perry, 2013) and experience from the preliminary project (Wågbo, 2013).

### 5.3.1 Goal

The goal was to assess and compare functional appropriateness and usability of EHR data presented to patients with the information visualization techniques that was found in the state-of-the-art review described in chapter 4, with a the a tabular representation similar to current solution at Helsenorge.no.

### 5.3.2 Usability lab

The tests were carried out at the NTNU's usability lab at NSEP. In this lab, equipment for video and audio recording and eye tracking is available. This was used in order to ease the work of observation. Since there was only one observer present during the test, this was essential as observation could then be done both during the test and in retrospect.

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<sup>18</sup> Norwegian title which translates to "Practical User Testing"



### **5.3.2.1 Video and audio recording**

Video and audio were recorded of all tests. The video was close up image of the participant, giving the opportunity to view their facial expressions as they progressed through the test. Combining this with an audio recording, it enabled for a more thorough retrospective analysis of the tests. Audio was recorded through the whole test, so that both the user tasks and the interview afterwards were captured.

### **5.3.2.2 Tobii Eye Tracker and Tobii Studio**

Tobii Eye Tracker and Tobii Studio were used to record and analyze the user's interaction with the user interface as they executed the use cases given in the test.

The eye tracker is a piece of hardware which registers the user's eye movement through sending infrared light into the user's eye sockets and recording the reflection through two infrared cameras.

Tobii Studio is the software that was used to record the screen, the user, the user's eye movement and audio of each test session. It provides a calibration process to link the user's eye movement to where the user is looking on the screen. When a recording is replayed, the eye movement is visualized in the user interface as the test progresses. This way it was easy to see the users' focus points in the user interfaces.

## **5.3.3 Prototypes**

The prototypes were two different graphical user interfaces of the same underlying system. This ensured that everything except the way the health data was presented was equal in all tests and independent from the presentation. The prototype that utilized information visualization techniques is called "EPHVis", which is shown in Figure 5.1, and the prototype that used a tabular presentation is called "HMU", which is shown in Figure 5.2. The two prototypes are described in greater detail in chapter 6.

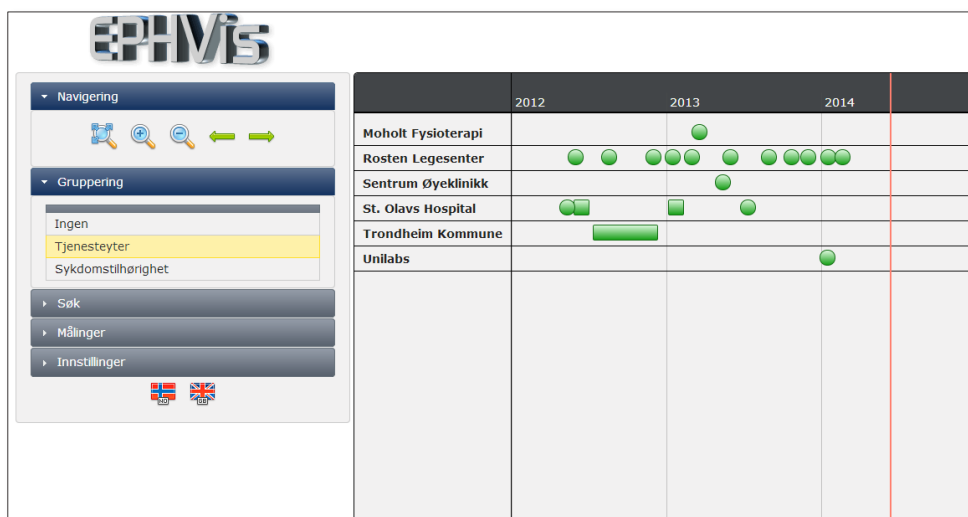


Figure 5.1: Screenshot of EPHVis

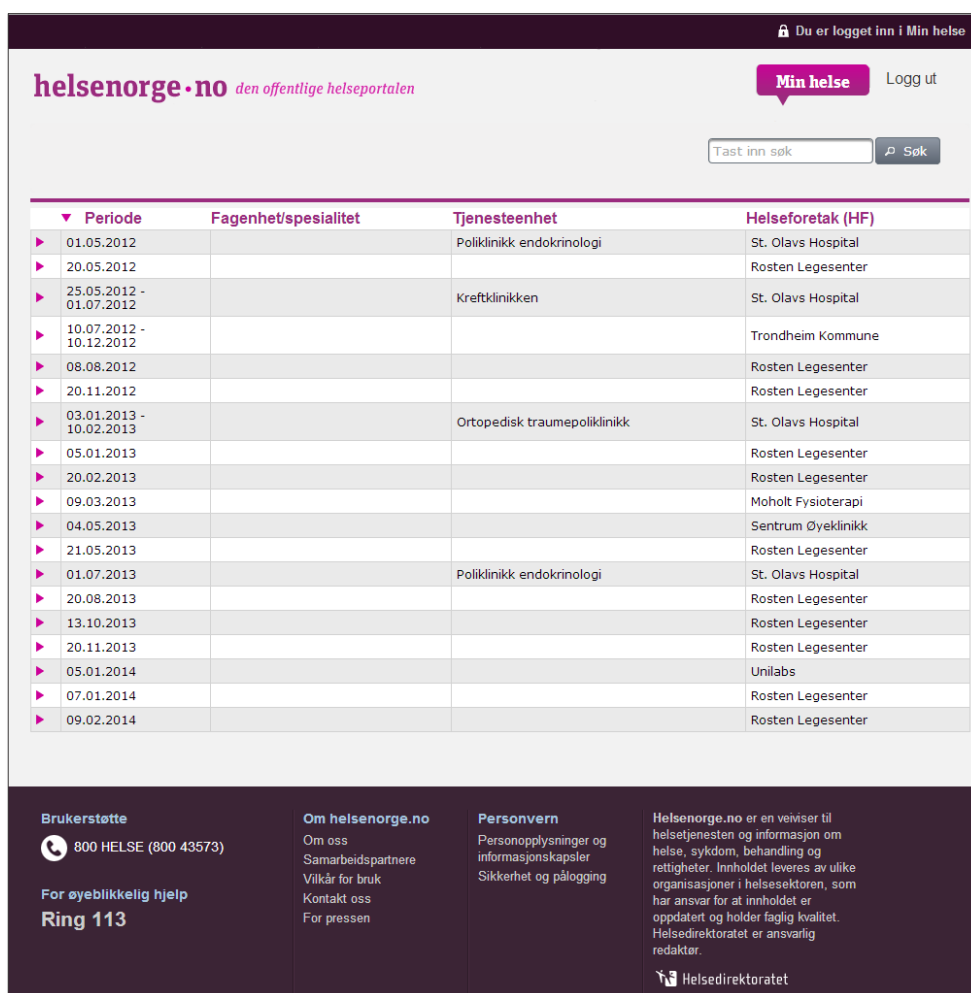


Figure 5.2: Screenshot of HMU

## 5.3.4 Test design

Each participant tested the system in individual sessions, with only the participant and the observer present. Before the test an oral introduction, telling the participant that they were going to test a Web application that gives patients' online access to their EHRs, that they were going to test a prototype that could contain unexpected glitches, and ensuring them that the test was to assess the system and not them personally. At the end of the introduction, the participant read and signed a consent and confidentiality statement.

Each test session was divided into 7 segments that were conducted in the same manner for each participant. The segments are given in chronological order below.

- 1) Preliminary question
- 2) Patient case
- 3) Preparations
- 4) User tasks
- 5) Retrospective interview
- 6) SUS schema

The test, as it was given to the participants can be found in Appendix D.

### 5.3.4.1 Preliminary questions

Participants were given a set of preliminary questions at the start of the test. These questions mapped the participants' demographic data, if they had any educational or professional affiliation to healthcare and their computer literacy. The questions were given on a piece of paper which the participants filled out themselves.

### 5.3.4.2 Patient case

Due to privacy restrictions on health records, the tests were done on a fictive dataset. To make the test realistic, the participants were to play the role as a support person to a fictive patient. They were given a background story to familiarize themselves with the patient behind the dataset that they were going to use during the test and the motivation for the user tasks they were going to perform. The background story is given below.

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*Per Pasient is a 70 year old male from Trondheim, Norway. He was diagnosed with diabetes type 1 at the age of 50. He has lived with this condition without complications the past 20 years.*

*Almost four years ago Per was diagnosed with prostate cancer. He was quickly admitted to hospital and the tumor was surgically removed. Although the surgery was successful, Per has been to the doctor on a regular basis the past years to make sure the cancer doesn't return.*

*Since Per is getting older and has problems remembering, he has asked you to be his personal support, to help him on his way to better health. In this context you have gained access to Per's personal patient record, conveniently available on the Web. Per and you have together identified some tasks you have to achieve to gain a better understanding of Per's health the past years.*

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### **5.3.4.3 Preparations**

Before the user could start the user tasks, some preparations were made. First, the eye tracker was calibrated to fit the participant's eyes. The participants were made aware that everything from this point onwards would be recorded. They were then reassured that this was a test of the system and not them personally, so they should not be concerned with their own performance. After this, they were encouraged to think-aloud as they executed the tasks and made aware that the user tasks would proceed without, or with very few, interruptions from the observer. If they were stuck at a task they could ask the observer, but they should always try to solve the tasks themselves first. To help the participants start the think-aloud process, reading the task aloud before they executed it was suggested to them.

### **5.3.4.4 User tasks**

After the preparations were done, the participants were given the list of tasks they were to execute and the structure of the tasks was explained to them. The tasks were constructed as a goal, which stated what the purpose of the task was, and the conceptual steps to achieve that goal. These tasks mainly concerned browsing health data and finding information.

They were informed that they were free to choose how to solve each step. The tasks were worded in a way so that it did not fit the names of the functions (i.e. buttons or headings) in the user interface. This was done to avoid participants from instantaneously coupling a task to a function.

Thereafter the recording was started and the execution of tasks began. The tasks were identical for both prototypes, with one minor exception. The steps in task 4 were dependent on which prototype that was tested. The user tasks were as follows:

- 1) Goal: Find Per's hospitalization at St. Olavs in 2012, find out which information that exists about the admission.
  - a. Find the event (Hospitalization at St. Olavs 2012)
  - b. Click on the event and see what is written about it
- 2) Goal: Find the last time Per was at his GP and find out what PSA was measured to then.
  - a. Find the last event at Rosten medical center
  - b. Click on the event and see what is written about it
- 3) Goal: Find out when Per was at his last diabetes checkup. These sometimes take place at St. Olavs and sometimes at Rosten medical center.
  - a. Find the last event tied to diabetes
  - b. Inspect when the event took place
- 4) Goal: Get an overview of hba1c- and PSA-tests that has been taken.
  - a. (For EPHvis only) make a diagram of hba1c- and PSA-tests
  - b. (For HMU only) find events with hba1c- or PSA-tests and inspect
- 5) Goal: Find the last time Per was at an MRI examination and find out which diagnosis that was given at this examination.
  - a. Find the last MRI examination Per has been to
  - b. Click on the event and see what the diagnosis was

#### **5.3.4.5 Retrospective interview**

After the user tasks a retrospective interview was held. This interview contained two parts, one to investigate the participants' overview and comprehension of the dataset they had been browsing, and one to investigate their thoughts and impression of the system they had been tested.

##### ***5.3.4.5.1 Participants overview and comprehension of the dataset***

This part of the interview was structured and contained concrete questions about Per's health data. The purpose of these questions was to assess what kind information the participants' gotten from the way health data was presented to them. This interview investigated how much explicit information, i.e. information addressed through the tasks, and implicit, i.e. information that were available in the presentation, but not inspected through the tasks they had

executed. The questions were purposely made to be quite hard and extensive to map differences between the different ways of presenting health data.

- 1) Approximate how many service providers (eg St.Olavs) had Per been to (how many "places" had Per been)?
- 2) Do you remember the name of some of these service providers (where had Per been)?
- 3) Do you remember if Per had been at St. Olavs this year (2014)?
- 4) In task 1 you were to find a hospitalization in 2012 at St. Olavs, had Per been hospitalized at St. Olavs sometimes after this?
  - a) (If yes) Roughly, when was this?
- 5) In task 5 you were to find an MRI examination. This study took place at Unilabs. Do you remember if Peter had been at Unilabs any other time than this?
- 6) Approximately, when was the MRI examination you found in task 5?
- 7) Roughly, how often was Per to his GP (at Rosten medical center)?
- 8) In task 4 you were to obtain an overview of hba1c and PSA tests, did you see any connection between the values?

#### ***5.3.4.5.2 Thoughts and impressions on the system***

This part of the interview was very open and was semi structured. Five questions provided a foundation in the interview, however these were adapted and supplemented to fit the discussion in each interview. The five fundamental questions were:

- What did you think of the system?
- What was difficult?
- What was easy?
- How would you experience getting your own health record presented in this way?
- Do you have any suggestions for improvement or other feedback?

#### **5.3.4.6 SUS form**

At the end of the test the participants were asked to fill out a SUS form. System usability scale (SUS) is an ISO standard<sup>19</sup> form for high-level usability assessment that sets a score between zero and a hundred on the users' subjective

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<sup>19</sup> ISO 9241-11

reactions to using the system, i.e. the user satisfaction (Brooke, 1996). In the form the users were asked to grade ten statements on a scale from one (strongly disagree) to five (strongly agree). The SUS form that was used can be found in **Error! Reference source not found.**

The SUS-score was calculated as follows:

1. Every question was given points from 0 to 4 as this:
  - a. Questions 1,3,5,7 and 9 were given the score provided on the form minus one.
  - b. Questions 2,4,6,7 and 10 were given five minus the score provided on the form.
2. The total score was multiplied by 2.5.

### 5.3.5 Recruitment of participants

10 participants were recruited through friends, family, colleges and acquaintances, 5 participants for each way of presenting EHR data.

The criteria for selection, was that the participant knew how to use a Web browser on a normal computer and had no earlier knowledge of the prototypes. They were also selected to vary somewhat in age, gender and computer literacy.

As a compensation for time spent, a theater gift card was given to those who participated.

### 5.3.6 Functional appropriateness

Functional appropriateness is defined by ISO/IEC as the “degree to which the functions facilitate the accomplishment of specified tasks and objectives”<sup>20</sup>. Functional appropriateness is sometimes referred to as “suitability”. The specified tasks and objectives are given in section 5.3.4.4.

The functional appropriateness of the prototypes was assessed by observation of how participants approached the given set of user tasks, and their remarks during the testing and in the retrospective interview. Especially important in this assessment was the participants’ approaches of tasks seen in relation with the overview and comprehension they had gained of the given dataset.

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<sup>20</sup> ISO/IEC 25010

## 5.3.7 Usability

Usability is defined by ISO/IEC as the “degree to which a product or system can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use”<sup>21</sup>.

### 5.3.7.1 Effectiveness

Effectiveness is the degree to which users are able to perform the tasks supported in the user interface. This was assessed by a set of success criteria and the accuracy in performance of user tasks.

### 5.3.7.2 Efficiency

Efficiency is how efficient the users are in performing user tasks in the user interface. This was assessed by the nature of the approach the users took and the time they used on the tasks. For efficiency to be meaningful, it was assessed as an average of the participants (Toftøy-Andersen & Wold, 2011).

### 5.3.7.3 Satisfaction

Satisfaction is the user’s comfort and the positive attitudes towards the use of the system (Frøkjær, Hertzum, & Hornbæk, 2000). Satisfaction was assessed through the retrospective interview and the SUS forms participants filled out.

## 5.4 Visualization feasibility analysis

This section describes an analysis of large-scale usage that was done in this project. Part of the PAsTAs project is to conduct a large-scale survey, where a selection of users of health care services are invited to answer questions related to their health care usage in a two-year period. Those who agree are presented with the health services they have used in a visualization that utilize state-of-the-art EHR visualization techniques. They can either answer a questionnaire online or get a paper version. An analysis of the submission thus far to the online questionnaire was used to investigate the feasibility of the visualization. The visualization the participants are presented with is described in further in chapter 6, under the section about PAsTAs Web.

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<sup>21</sup> ISO/IEC 25010



## 5.4.1 Goal

The goal is to investigate the feasibility of utilizing information visualization techniques derived from state-of-the-art EHR visualization when presenting health data to patients.

## 5.4.2 Analysis design

Feasibility was analyzed by investigating two questions:

- 1) Was the drop rate in participation throughout the questionnaire affected by the introduction of the visualization?
- 2) What was the responses from participants when asked if the presentation is correct (referring to the visualization)?

### 5.4.2.1 Drop in participation caused by visualization

The PAsTAs online questionnaire contains 38 questions<sup>22</sup>, divided into 11 steps. The questionnaire utilizes stepwise submissions for each of these steps. This means that each time a participant continues from one step to another, their preliminary answers are saved to a central store. Therefore, even though a participant does not finish the whole questionnaire, the answers they gave in the steps they did complete is not lost.

The questionnaire is in a step-by-step manner, all questions are optional to answer, but some steps and questions are conditioned on certain answers on specific questions, i.e. a participant will only be confronted with a conditional question/step if a former question is answered in a certain way. The participants can traverse forwards and backwards through the steps. Each forward traversing results in a stepwise submission.

No explicit data was saved on which step in the questionnaire a submission originated from<sup>23</sup>. Because of this, the submissions could only be used to estimate how many people partook at each point in the questionnaire. This estimation was based on two things:

- 1) The number of stepwise submissions participants committed, i.e. the number of times they clicked “forwards”.
- 2) The number of known participants at any location within the questionnaire. This was based on the number of responses to each question combined with the position of the question in the questionnaire. E.g. if there are X answers to a question, there are X known participants at that point in the questionnaire, and all of them must have participated

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<sup>22</sup> Excluding the optional comment at the end, and not counting sub-questions.

<sup>23</sup> Except the last one, which was marked to reveal that the participant had finished the questionnaire.

in the questionnaire up until that question. This means that it was the peaks in number of answers that determined how many participants were known to still be partaking in the questionnaire, and not the number of answers on each individual question. E.g., let us say there are 1000 answers submitted to question number 1, and 1200 answers to question number 5. Because question number 1 is given before question number 5, it is assumed that all 1200 of those who answered question number 5 also participated at the questions before, i.e. question 1, 2, 3 and 4.

#### **5.4.2.2 Responses from participants when asked if the presentation was correct**

The first question after the visualization was introduced, asked if the presentation of the participants personal health data was correct. This was a multiple-choice question, where participants could answer with one out of five answer options:

- 1) “Yes. It looks correct.”
- 2) “Do not know, do not remember.”
- 3) “Partially correct, but some services are missing.”
- 4) “Partially correct, but there are some services that I have NOT used.”
- 5) “No. Everything is wrong.”

##### ***5.4.2.2.1 Understanding and correctly interpreting visualization***

Participants should be presented with their own health data and therefore it should be correct, however, the health data used in the survey were only gathered from some healthcare organizations, and thereby may not be complete. Therefore, participants should select one of the first two answer options. It is probable that those who responded with these answers understood and had correctly interpreted the visualization they were presented.

##### ***5.4.2.2.2 Not understanding the visualization***

It is assumed that the participants that did not *understand* the visualization, and realized so, all responded with “do not know, do not remember”.

##### ***5.4.2.2.3 Misinterpretation the visualization***

Those who *misinterpreted* the visualization are harder to identify, since their misinterpretation could result in a submission of any of the answer option. Nevertheless, they are most likely to result in one of the three latter answer options.

### **5.4.3 Equipment**

As mentioned, PAsTAs used a tailored version of the application used in the online questionnaire in this project, called PAsTAs Web. Also in this project, the self-developed SurveyAnalyzer was used to convert the submissions in OWL, into Microsoft Excel file format (XLS). Microsoft Excel 2013 was then used for the data analysis.

# 6 Implementation

This chapter gives insight to the applications that was developed and used in this project.

There were two different applications. Firstly, the application that was used in the test of functional appropriateness and usability, called Epicurus Personal Health System (EPHS). This application provides two different user interfaces called EPHVis and HMU. And secondly, the application that was used in the PAsTAs project, called PAsTAs Web.

Common for EPHS and PAsTAs Web, is that they are designed upon the same principle. They use an OWL ontology as their foundation. This ontology provides a conceptual way of describing visualizations of temporal events. Kompanitsa et al. concluded in their research that medical data visualization methods use hard coded GUIs that offers very little flexibility, and that this needs to be replaced by generic methods. And suggests that the problem can be solved on the model level by providing semantic interoperability not only for the medical data exchange process, but for the data visualization process as well (Kopanitsa, Hildebrand, Stausberg, & Englmeier, 2013).

## 6.1 Ontology

Although the PAsTAs ontology is slightly different from the EPHS ontology, they are fairly similar. The EPHS ontology is a revision of the PAsTAs ontology. The PAsTAs ontology was designed to visualize a patient's health services, and was slightly changed to facilitate for reasoning with more extensive health data.

The PAsTAs ontology also provided a way to construct conceptual visualizations of questionnaires. Thus, making it possible to include a health services visualization into a questionnaire, as was done in the PAsTAs project's survey. This extension will not be discussed further in this report; nonetheless, this sort of extension is another example of why ontological conceptual structure of visualizations can provide an elegant solution.

This section describes the core ontology of EPHS. The core ontology consists of a set of classes and roles, which defines the conceptual visualization of health records. Patients' health records can be defined by instantiating these classes with individuals. These individuals can then be parsed by systems that provides a suitable visualization, constructed according to the conceptual visual structure. Together, these individuals and the core ontology constitute the EPHS ontology.

Thus, this ontology constitutes the interface between EPHS (the visualization software), and the data sources (EHRs).

It is important to note that the ontology, including the individuals, is not associated with a user interface. It merely defines the conceptual structure of the visualization. This concerns things such as the order of visual element, icons, images and text. Thus, it is not restricted to one specific visualization technique. This is underpinned by the fact that EHR provides two different user interfaces, EPHVis and HMU.

Currently the main ontology is currently restricted to conceptual visualization of temporal events that can have details about them. All details must have a title and a value. However, because of the open world assumption in Semantic Web, this main ontology can be extended as needed.

### 6.1.1 Classes

The main ontology consists of eight classes<sup>24</sup>. Figure 6.1 below illustrates the classes of the core ontology as a graph. The directed edges yields OWL's native abstract role "hasSubclass". This role is used to describe the class hierarchy in the ontology. A subclass is a discrete sub group that has a set of shared characteristics. Some of these characteristics are shared with larger group, which constitutes the parent class. Thus, a subclass inherit its parent class' characteristics.

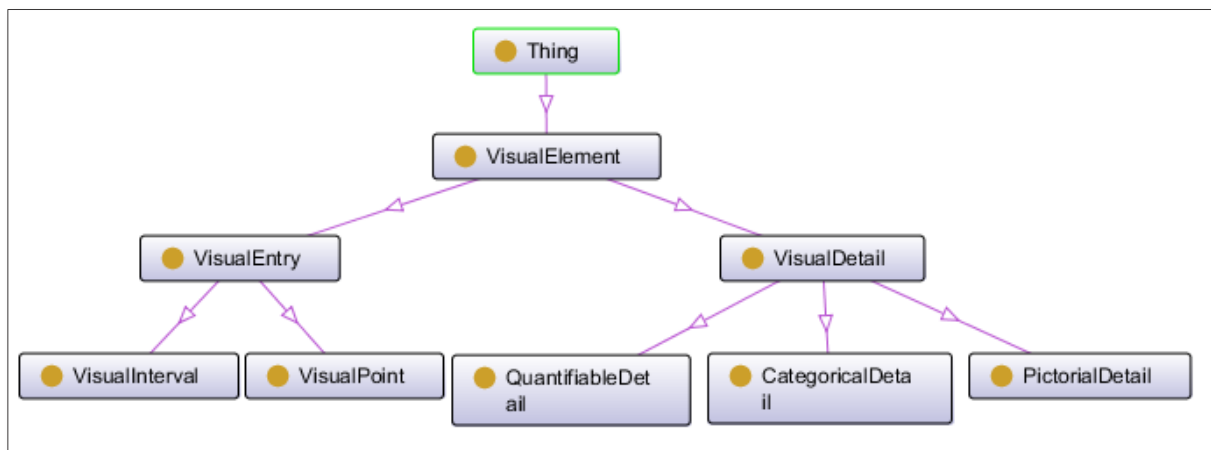


Figure 6.1: Class structure of main ontology.

*VisualElement* is the class that describes all visual elements in the conceptual visualization. It is a subclass of the native OWL-class *Thing*, and parent to two subclasses: *VisualEntry* and *VisualDetail*.

<sup>24</sup> The native OWL-class "Thing" is not counted as one of these.

The *VisualEntry* class describes visual entries in to the visualization. In practice, this class describes temporal health events. It has two subclasses: *VisualPoint* and *VisualInterval*. These are the points and intervals in the visualization, i.e. events that are momentary and events that span over a period of time, respectively.

The *VisualDetail* class describes all details of visual entries. All individuals that instantiate this class must consists of a title and a value. This class has three subclasses: *CategoricalDetail*, *QuantifiableDetail* and *PictorialDetail*.

*CategoricalDetail* describes any detail that is categorical, i.e. details that facilitate categorization. This is used for things such as service provider or illness affiliation, which can be used to categorize events.

*QuantifiableDetail* describes any detail that quantifiable. These details have numeric values, and are used for things such as blood measurements or a patient's weight.

*PictorialDetail* describes any detail that is pictorial, i.e. can be presented as an image. In practice, these details have values that are URLs to external sources, where the images can be retrieved.

## 6.1.2 Abstract roles

The core ontology defines one abstract roles: *hasVisualDetail*.

*hasVisualDetail* is a role that can connect individuals that instantiate the class *VisualEntry*, or one of its subclasses *EntryPoint* and *EntryInterval*, to an individual that instantiate the class *VisualDetail*. Hence, it can be used to represent that a visual entry has a visual detail.

## 6.1.3 Concrete roles

The core ontology defines six concrete roles: *hasStartTime*, *hasEndTime*, *hasTitle*, *hasValue*, *isVisible* and *hasIcon*.

*hasStartTime* and *hasEndTime* describes the start and end time of something, respectively. These are used to set the time of visual entries.

*hasTitle* sets a title to a visual element. It is used to title visual entries and visual details.

*hasValue* sets the central value of a visual element. This is used to set the values of visual details.

*isVisible* is a Boolean role which can be used to define if a visual element should be explicitly visualized or not on screen. The purpose of this role is to enable adding information about the visualization that can affect the visualization, but

the details of which is hidden for the user. For example, this could be used to supply categorical details for grouping events, but that the value of which cannot be read by the user.

*hasIcon* sets icons on visual elements. This role is restricted to be an URL. This URL should refer to an external source where the icon can be retrieved. This property was not utilized during the test in this project. However, it enables inclusion of icons in the visualization.

### 6.1.4 Example

As it might be a bit hard to understand how this falls together, this section gives a short example of how some this ontology can be used to represent conceptual visualization of health data.

Let us say a patient has an event: A doctor consultation at St. Olav’s Hospital. This event took place June 27<sup>th</sup> 2014.

As this was a consultation, it is considered to be a momentary event. Thus, we create an individual that instantiate the class *VisualPoint*. We use the concrete role *hasStartTime* to connect the event’s time given as a literal, to this individual. As this was a doctor consultation, we can represent this by giving our *VisualPoint* individual the title “Doctor consultation” by using the concrete role *hasTitle*.

In addition, we want to represent the fact that St. Olav’s Hospital was the service provider in this event. Thus, we add a detail to the *VisualPoint* individual. We want to be able to categorize events by service provider at a later time, therefore we create an individual that instantiate the class *CategoricalDetail*. We give this individual the title “Service provider” via the concrete role *hasTitle*, and give it the value “St. Olav’s Hospital” by the concrete role *hasValue*.

## 6.2 EPHS

This section describes the EPHS system and its two user interfaces EPHVis and HMU. This description will focus on the visual interfaces as this is most relevant for this report, but first a short introduction to the underlying system is given.

An overview of EPHS is illustrated in the figure below.

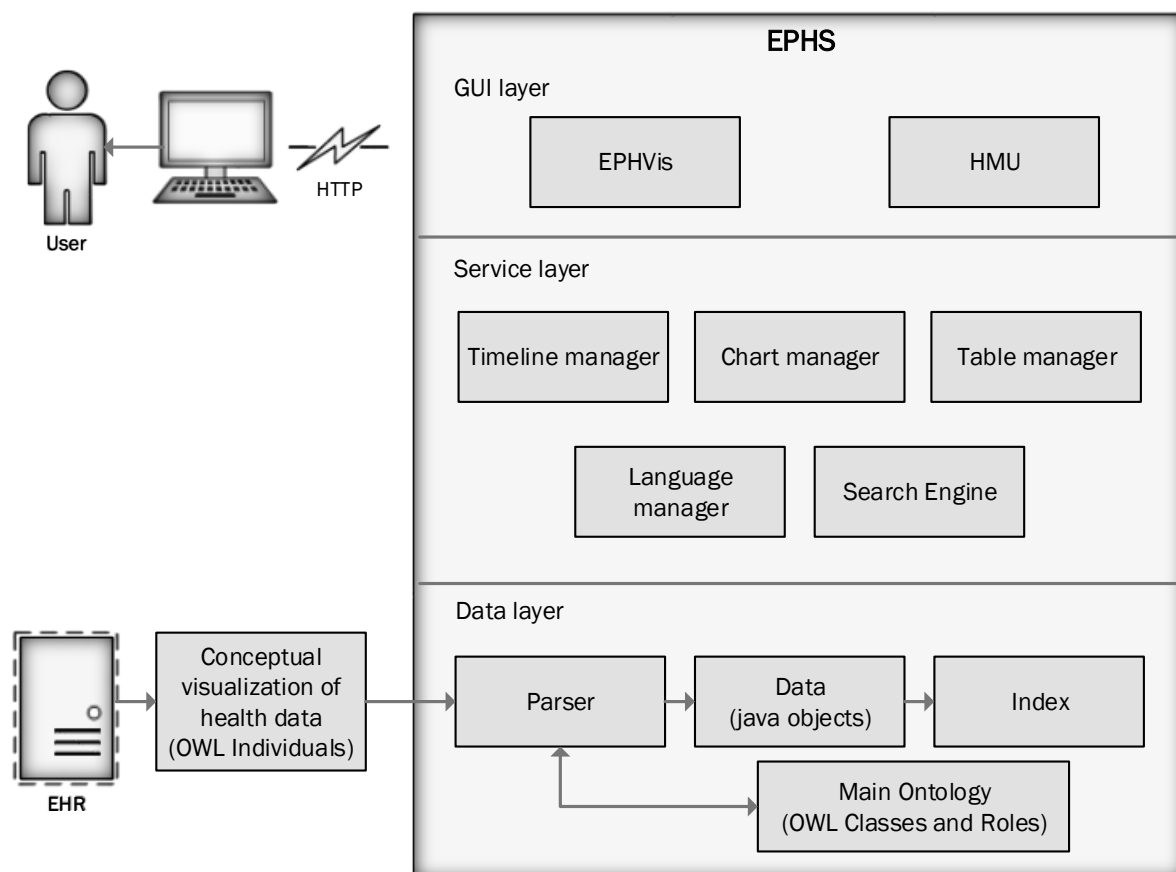


Figure 6.2: Overview of EPHS.

The system uses the main ontology, described earlier in section 6.1, as its foundation. The conceptual visualization of health data is input as an OWL file through an ontology parser, which interprets this according to the main ontology. Just as the ontology, the system is unbiased to the underlying health data, and simply treats the data as temporal events that may have a title, and may contain some additional details, and all event details are treated as archetypes that consists of a title and a value. The IRIs derived from the ontology individuals are used as identifiers in the system, in order to appropriately group and separate data. After this, the patient data is indexed for the Apache Lucene search engine.

Event details are generally treated as text that is preview in the on-demand details according to their visual definitions in the ontology. However, as mentioned in the ontology section above, details can be further specified as categorical, numerical or pictorial. Categorical and numerical details is treated a



bit differently by the two interfaces; this is described in their respective sections below. Pictorial details are treated as text by the system, but their value is presented by the interfaces as thumbnails, which are hyperlinked to the external picture<sup>25</sup>. Clicking a thumbnail will send the user to the external picture.

After the data has been parsed into the system and indexed, the system creates a suitable interface, i.e. EPHVis or MHU, and is ready to presents the health record to the patient.

## 6.2.1 EPHVis

This section describes the EPHVis user interface and its functions. EPHVis was developed by using information visualization techniques derived from state-of-the-art EHR visualization, as described in chapter 4. Some adaptations were made in order to make the development feasible and to incorporate support of probable use cases of patients were the overall intention is browsing EHR data.

### 6.2.1.1 Overview and on-demand details

The user is first presented with a timeline overview of their temporal health events, as shown in Figure 6.3.

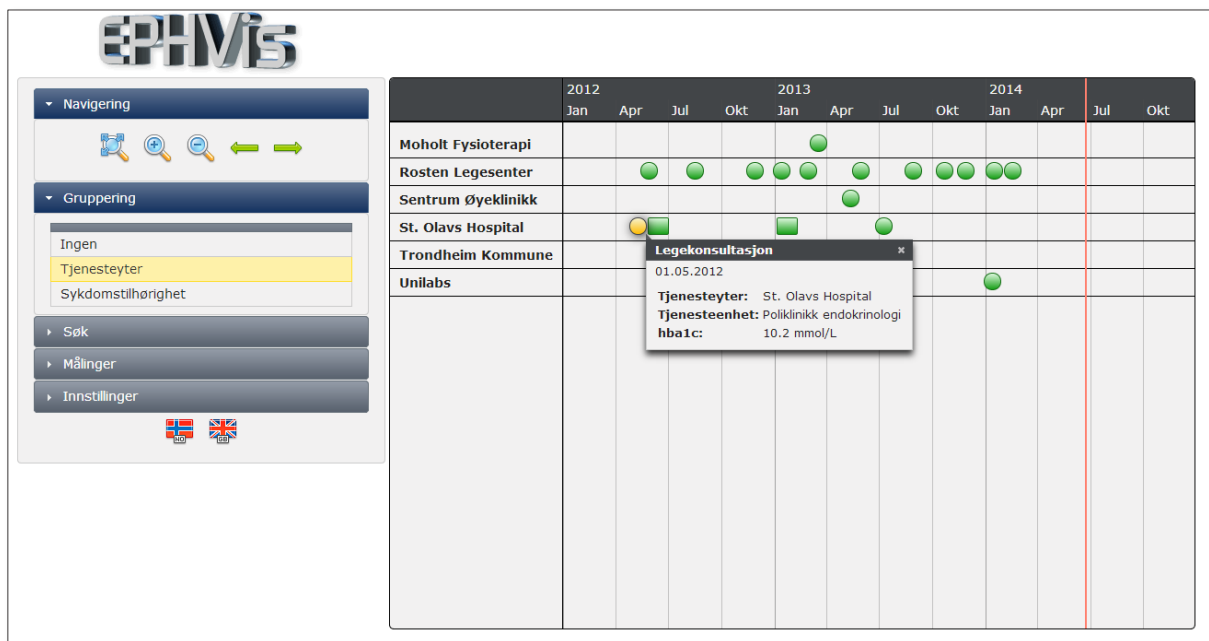


Figure 6.3: EPHVis - Preview of on-demand detail.

In the timeline, momentary events are represented as round dots, and events that goes over period of time as rectangles. The vertical lines represents the time

<sup>25</sup> A “thumbnail” is a size-reduced version of an image.

aspect, the red line visualize the current time. The horizontal lines separate events into lanes according to their affiliation to some category.

As illustrated in the figure, the user can get on-demand details about an event by clicking these representations with the cursor. They are then highlighted yellow and a tooltip with the available details of the event appears besides it.

The user can zoom in and out on the timeline by hovering it and scrolling. Panning can be done by pressing the timeline and dragging it with the cursor left or right. The left menu allows the user to navigate the timeline by using buttons instead. This also has an “auto-zoom” button which sets a suitable zoom on the timeline so all events are visible.

The left side menu also provides some additional functions that can be accessed by the buttons. These are described in the sections below.

### 6.2.1.2 Alternate event grouping

The function besides navigation that is initially visible for the user in the left side menu is “grouping”. This function provides all the available categorical detail titles that was retrieved during the OWL parsing process. By clicking on one of these titles, the timeline visualization will change to group events according to this categorical detail. I.e. if an event has a categorical detail with the title “disease affiliation” and this title is selected in the menu, then the timeline visualization will group events in lanes according to their value of the “disease affiliation” categorical detail. Figure 6.3 in the previous section had events grouped by service provider. The figure below shows the same timeline, but where events instead have been grouped by “disease affiliation”.

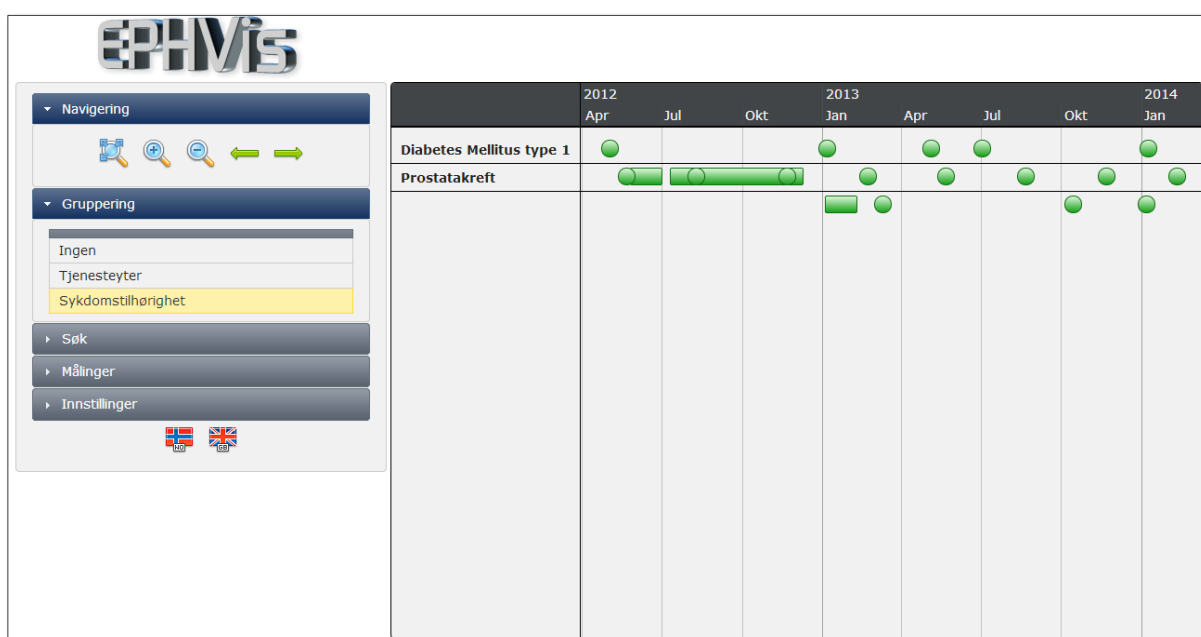


Figure 6.4: EPHVis - Preview of grouping by disease affiliation.

The events that does not have a categorical detail with the title “disease affiliation” are shown below the lanes.

As has been implied, this grouping function is dependent on the underlying health data. The categorical details that are affiliated with events constitutes which lane groupings that are available. “Service provider” is set to be the default lane grouping, as this is probable to be available in health records. However, if no categorical details are available this is not a problem, the timeline will then simply not group events into lanes.

### 6.2.1.3 Search filtering

The second function in the left side menu is the search filtering. This function depends on the Apache Lucene search engine to find events relevant for the users search queries. The resulting events of a search query is given as a list below the search input field, sorted by how well the query correspond with the event. The timeline also visualize the search results by coloring event representations according to their hit rate. The color intensity correspond to how relevant an event is for the query, events that has maximal high hit rate on the query will be colored with an intense red, this color will fade as the hit rate decrease. Events that are irrelevant for the query are grayed out. Additionally the event representations in the timeline are numbered to correspond with the result list below the search input field.

Figure 6.5 illustrates the concept. Here the user has searched for events relevant for the query “diabetes” and received five events.

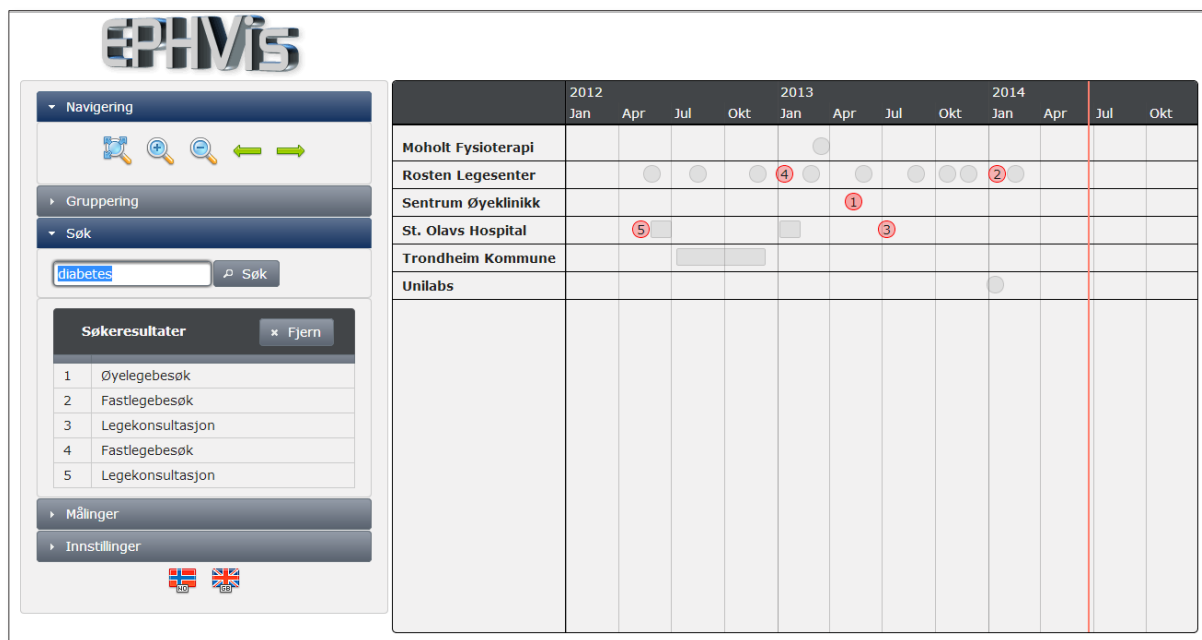


Figure 6.5: EPHVis - Preview of search

The user can, as always, click the event representations on the timeline to get on-demand detail. However, it is also possible to click the events in the search result list. This will result in the same, a tooltip with the details will occur besides the event representation in the timeline.

### 6.2.1.4 Chart builder

The third function in the left side menu is the chart builder.

In EPHS, the values of numerical details are when possible interpreted by the chart manager into a numeric value and a measurement unit. This is done in order to build uniform charts of the measurements. The measurement units are interpreted in order to make sure that only measurements that have the same units are put on the same scale. This ensures that the patients are provided with charts that are correct, and not misleading. The chart manager also identifies all the different measurements that are in the patient data, by comparing the titles of numeric details and their measurement unit.

In the EPHVis interface, the chart builder is found under the “measurements” menu option. Here a list of the different types of measurements that was found in the patient data is presented. The user can then select the measurements that is to be visualized and click “build diagram” to visualize the measurements as a line chart.

Figure 6.6 below illustrates an example where the different measurements that was found in the health data was “PSA” and “hba1c”. The user has selected both and this resulted in a graph that previews the measurements in the same chart.

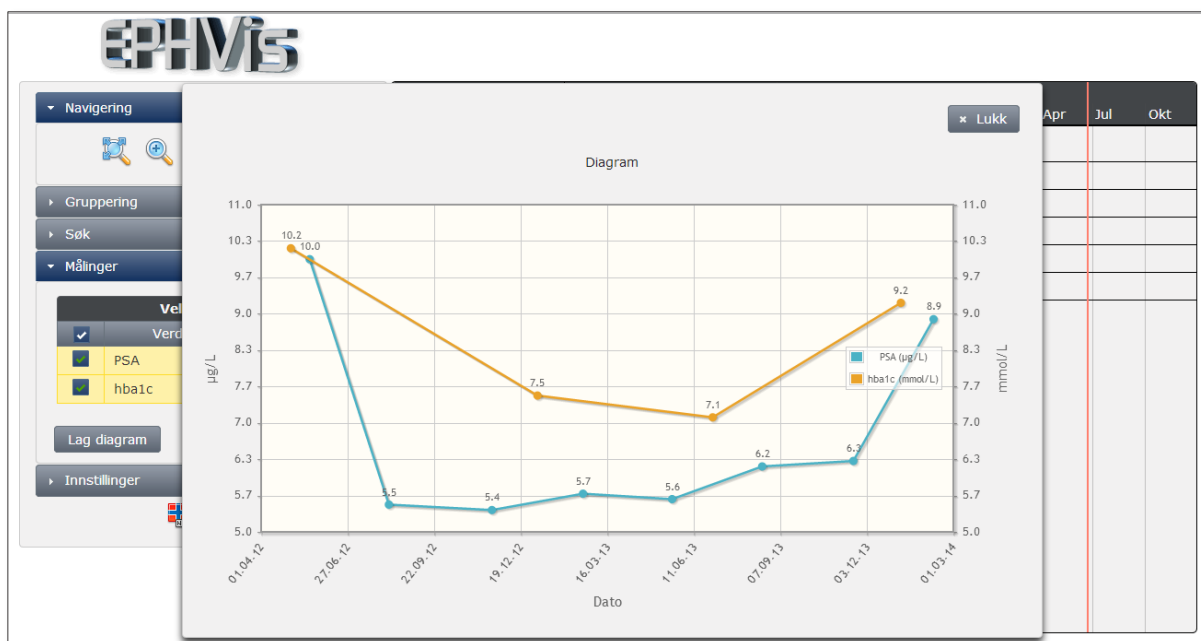


Figure 6.6: EPHVis - Preview of periodic measurements line chart.

The x-axis in the line chart gives the date of the measurements and the y-axis shows their numeric value. If a measurement in the graph is hovered with the cursor, a tooltip occurs which gives the date and value of the measurement in text.

### 6.2.1.5 Customizability and language

The EPHVis interface also comes with some layout customizability and language preferences.

The language manager in EPHS keeps track of languages, and the user's language preferences. The system will strive to provide everything on the preferred language, including the health data if this is available in the input OWL file. However, if the preferred language is not available in the patient data it provide the data on the language that is available.

Figure 6.7 illustrates the EPHVis interface with alternative layout and with preferred language set to English.

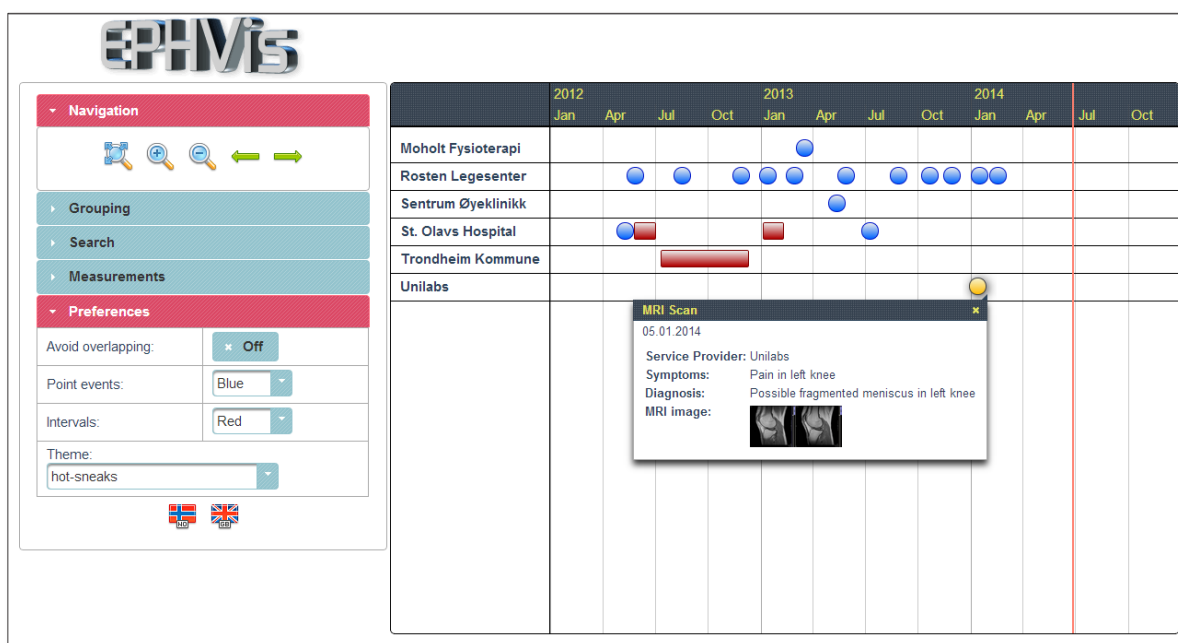


Figure 6.7: EPHVis - Preview of language and layout customizability.

## 6.2.2 HMU

This section describes the HMU user interface and its functions. HMU was developed to simulate the current solution for showing health service history at the “My health” service at helsenorge.no, therefore the name HMU which is an acronym for “Helsenorge Mash Up”.

### 6.2.2.1 Overview and on-demand details

The overview of HMU is in a tabular form, where events were represented as rows. The overview presents the columns “period”, “specialist unit/specialty”, “service unit” and “health enterprise” for each event. These columns correspond to the columns used at helsenorge.no.

Figure 6.8 below gives an example of the overview.

The screenshot shows the helsenorge.no website interface. At the top, there is a navigation bar with "helsenorge.no den offentlige helseportalen" and a "Min helse" button. Below the navigation bar is a search bar with the text "Tast inn søk" and a "Søk" button. The main content area displays a table with the following columns: "Periode", "Fagenhet/spesialitet", "Tjenesteenhet", and "Helseforetak (HF)". The table lists various medical events from 2012 to 2014. One event from 05.01.2014 is highlighted in pink, and its details are shown below the table. The details include the title "MR undersøkelse", symptoms "Smerte i venstre kne", diagnosis "Mulig fragmentert menisk i venstre kne", and an MR-bilde (MR image) showing a knee joint. The footer of the page contains four columns of information: "Brukerstøtte" (800 HELSE (800 43573)), "Om helsenorge.no" (Samarbeidspartnere, Vilkår for bruk, Kontakt oss, For pressen), "Personvern" (Personopplysninger og informasjonskapsler, Sikkerhet og pålogging), and "Helsenorge.no er en veiviser til helsetjenesten og informasjon om helse, sykdom, behandling og rettigheter. Innholdet leveres av ulike organisasjoner i helsesektoren, som har ansvar for at innholdet er oppdatert og holder faglig kvalitet. Helsedirektoratet er ansvarlig redaktør." (Helsedirektoratet logo).

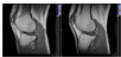
▼ Periode	Fagenhet/spesialitet	Tjenesteenhet	Helseforetak (HF)
▶ 01.05.2012		Poliklinikk endokrinologi	St. Olavs Hospital
▶ 20.05.2012			Rosten Legesenter
▶ 25.05.2012 - 01.07.2012		Kreftklinikken	St. Olavs Hospital
▶ 10.07.2012 - 10.12.2012			Trondheim Kommune
▶ 08.08.2012			Rosten Legesenter
▶ 20.11.2012			Rosten Legesenter
▶ 03.01.2013 - 10.02.2013		Ortopedisk traumepoliklinikk	St. Olavs Hospital
▶ 05.01.2013			Rosten Legesenter
▶ 20.02.2013			Rosten Legesenter
▶ 09.03.2013			Moholt Fysioterapi
▶ 04.05.2013			Sentrum Øyeklinikk
▶ 21.05.2013			Rosten Legesenter
▶ 01.07.2013		Poliklinikk endokrinologi	St. Olavs Hospital
▶ 20.08.2013			Rosten Legesenter
▶ 13.10.2013			Rosten Legesenter
▶ 20.11.2013			Rosten Legesenter
▼ 05.01.2014			Unilabs
<b>MR undersøkelse</b>			
<b>Symtomer:</b> Smerte i venstre kne			
<b>Diagnose:</b> Mulig fragmentert menisk i venstre kne			
<b>MR-bilde:</b> 			
▶ 07.01.2014			Rosten Legesenter
▶ 09.02.2014			Rosten Legesenter

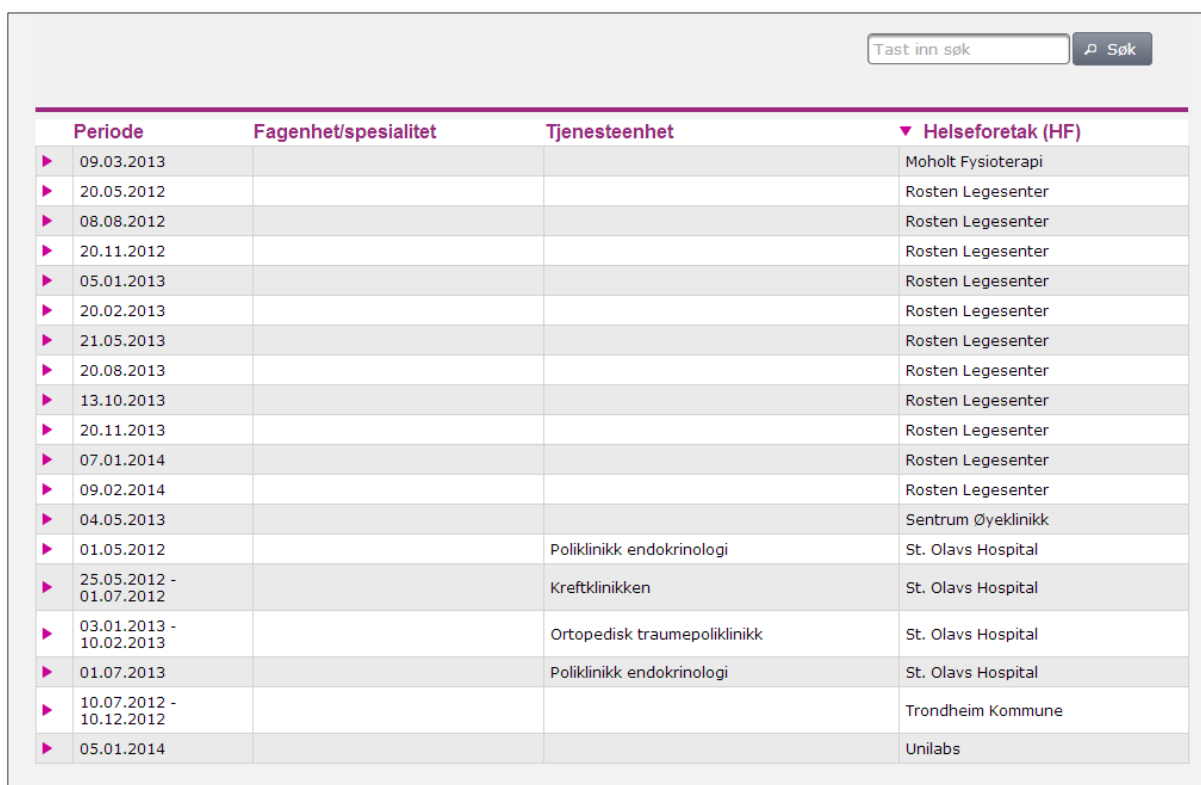
Figure 6.8: HMU - Preview of overview and on-demand detail.

If the user clicks on a row, the row is then highlighted with color and a section below the row expands to provide on-demand details about the event, as illustrated in Figure 6.8. The content in the on-demand details is previewed in the same manner as the details in the tooltips in the EPHVis interface.

Everything around the table and the search field are pictures that were added to simulate the surrounding layout. This will therefore not be included in figures in the sections below.

### 6.2.2.2 Sorting

The table was initially sorted by the “period” column, i.e. by time. In this way, the oldest event occurred first, and the newest last. However, the user could change this sorting by clicking the column headers. Figure 6.9 illustrates an alternate sorting, where the events are sorted alphabetically by “health enterprise”.



Periode	Fagenhet/spesialitet	Tjenesteenhet	▼ Helseforetak (HF)
▶ 09.03.2013			Moholt Fysioterapi
▶ 20.05.2012			Rosten Legesenter
▶ 08.08.2012			Rosten Legesenter
▶ 20.11.2012			Rosten Legesenter
▶ 05.01.2013			Rosten Legesenter
▶ 20.02.2013			Rosten Legesenter
▶ 21.05.2013			Rosten Legesenter
▶ 20.08.2013			Rosten Legesenter
▶ 13.10.2013			Rosten Legesenter
▶ 20.11.2013			Rosten Legesenter
▶ 07.01.2014			Rosten Legesenter
▶ 09.02.2014			Rosten Legesenter
▶ 04.05.2013			Sentrum Øyeklinikk
▶ 01.05.2012		Poliklinikk endokrinologi	St. Olavs Hospital
▶ 25.05.2012 - 01.07.2012		Kreftklinikken	St. Olavs Hospital
▶ 03.01.2013 - 10.02.2013		Ortopedisk traumepoliklinikk	St. Olavs Hospital
▶ 01.07.2013		Poliklinikk endokrinologi	St. Olavs Hospital
▶ 10.07.2012 - 10.12.2012			Trondheim Kommune
▶ 05.01.2014			Unilabs

Figure 6.9: HMU - Preview of alternative sorting.

### 6.2.2.3 Search filtering

Just as in the EPHVis interface, MHU provides a search function. This is essentially the same function; it depends on the Apache Lucene search engine to find events relevant for the users search queries. When the search function is used, all irrelevant events are filtered away from the table. Thus, only the events that resulted from the query is presented. Additionally, the events are sorted according to their hit rate on the search query, so the most relevant given at the top of the table and the least relevant is given at the bottom.

Figure 6.10 illustrates the same search that was done in the EPHVis description, in section 6.2.1.3. Here, the user has searched for events relevant for the query “diabetes”, and all but the five resulting events have been filtered away from the table.



The screenshot shows a search interface with a search bar containing the text 'diabetes' and a 'Søk' button. Below the search bar, it says 'Fant 5 treff!' (Found 5 hits!). A table displays the search results with the following columns: Periode, Fagenhet/spesialitet, Tjenesteenhet, and Helseforetak (HF). The table contains five rows of data.

Periode	Fagenhet/spesialitet	Tjenesteenhet	Helseforetak (HF)
▶ 04.05.2013			Sentrum Øyeklinikk
▶ 01.05.2012		Poliklinikk endokrinologi	St. Olavs Hospital
▶ 05.01.2013			Rosten Legesenter
▶ 01.07.2013		Poliklinikk endokrinologi	St. Olavs Hospital
▶ 07.01.2014			Rosten Legesenter

Figure 6.10: HMU - Preview of search.

In order to go back to the overview where all events are presented, the users has to click the “back” button.

## 6.3 PAsTAs Web

This section describes the PAsTAs Web visualization, and how it was integrated to the questionnaire.

As mentioned in the ontology section above, the visualization is defined by instantiating classes in the core ontology with individuals. Hence, the patient data that was used in PAsTAs Web did the same. Each patient had a series of individuals in the ontology, which constituted the conceptual visualization of their health service usage<sup>26</sup>.

When a patient initiated the online PAsTAs questionnaire, they were first prompted with a login, where they needed to provide a code they had been given in the invitation to the survey. When a patient logged in, their data was retrieved from an underlying data server, and incorporated into a template to

<sup>26</sup> Although they belonged to the same ontology, the individuals were kept in separate files.



create a tailored questionnaire that asked a series of questions adapted to their personal data. The data was visualized to the patient in a similar fashion to the example below in Figure 6.11.

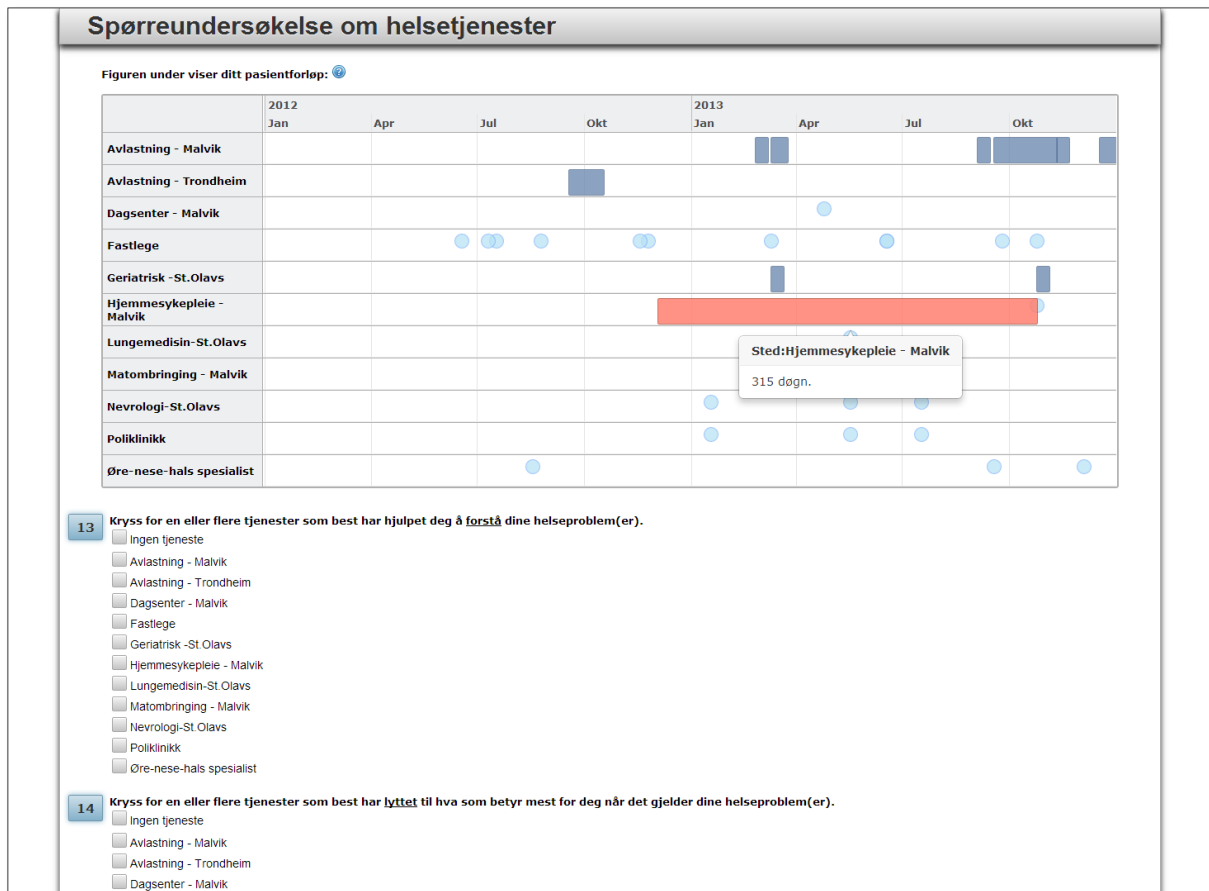


Figure 6.11: PAsTAs Web questionnaire (top of step 4)

The visualization that was included was a linear timeline that visualized events, i.e. usage of health services, as dots (light blue) and rectangles (dark blue). The dots represented events that were momentary, i.e. did not stretch out in time. The rectangles on the other hand, represented events that were over a period of time.

These events were horizontally placed along the x-axis according to when they took place. In addition, they were grouped according to their corresponding service provider. This grouping constituted the lanes in the visualization, i.e. the y-axis.

When an event representation was hovered by the mouse, it was highlighted with the color red, and a tooltip became visible just below the event. This tooltip gave some additional details to the event. Because of security requirements, an anonymization of the data was performed, which led to limited details. However, the number of days events lasted was available as on-demand details through these tooltips, in addition to the name of the service provider.

# 7 Results

In this chapter, the results from the online questionnaire, the test of functional appropriateness and usability, and the visualization feasibility analysis are stated respectively.

The main results in this project are the following:

- The responses to the online questionnaire suggests that patients are very interested in gaining online access to their health records, that they want extensive insight to their health data , and that they are very open to the idea of sharing any information the potentially were to supplement the health record with.
- The results from the test of functional appropriateness suggests that utilizing information visualization when presenting health data to patients is more functional appropriate than presenting them in a text-based tabular format.
- The feasibility analysis indicates that presenting health events as an interactive timeline is feasible for patients.

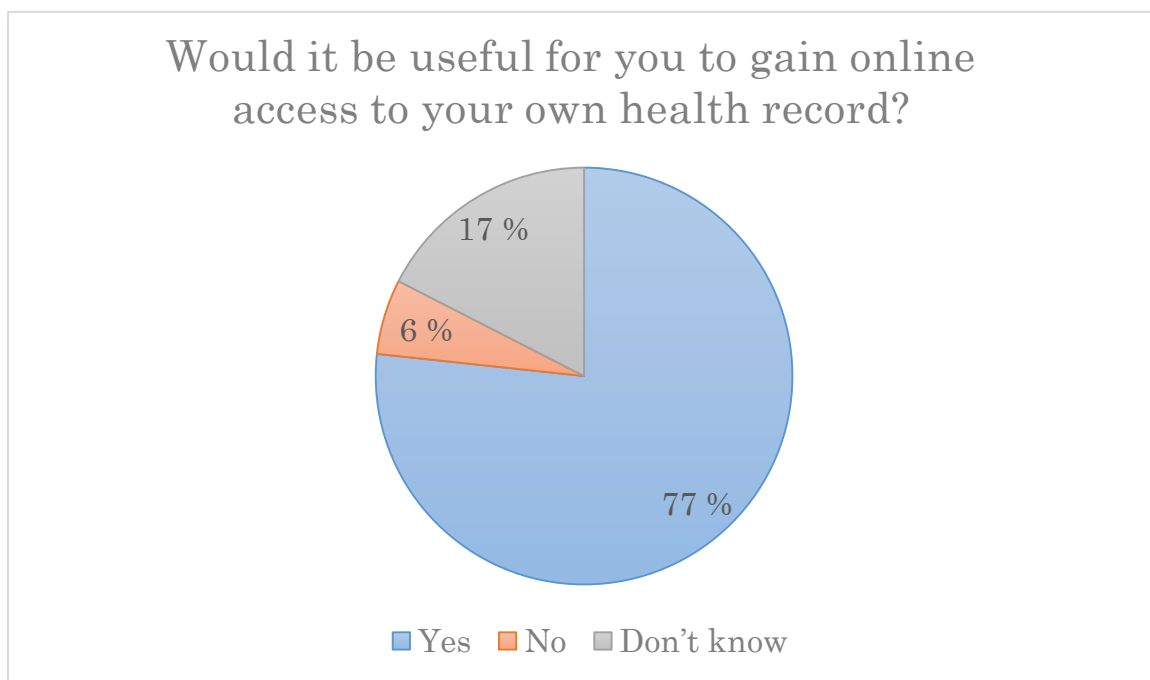
## 7.1 Online Questionnaire

This section will state the results from the online questionnaire. It focuses on the participants' answers and from these answers estimate the population proportion and mean. The credibility of these estimations is discussed in chapter 0.

A total of 103 people participated in the survey. The average age of the participants was 39 years with a median of 30 years. The youngest participant was 19 years and the oldest was 82 years. 47% of participants were female and 53% were male, and the average submission time was 9 minutes.

## 7.1.1 Perceived usefulness of gaining online access to personal health record

The patients were asked if they thought it would be useful for them to gain online access to their personal health records. An overview of the responses is given in Figure 7.1.



*Figure 7.1: Chart of participants' perceived usefulness access to health record.*

77% of the participants responded that they thought it would be useful for them and 17% responded that they did not know. Thus, calculating the 95% confidence interval as described in section 5.2.5.1, the proportion of people that thinks it would be useful to them in the population is estimated to be between 69% and 85%.

Out of the participants that responded “No” to the question, none had received chronic diagnoses or was educated in or worked with health, and all of them reported being in good health. On average, they rated their own health higher than those who responded “Yes”. Four of them reported using health services once year or rarer, and one reported using health services 1-3 times a year.

Those who responded “Don't know” also reported using less health services and perceived their health to be better than those who responded “Yes”, however not to the degree of those who responded “No”.

Of the 30 participants who had received chronic diagnoses, one person did not consider online access personal health record useful, and three responded that they did not know.

The hypothesis (**H1**) was that patients would consider it useful to gain insight to their own health record through a web interface. The corresponding null hypothesis was that the estimated population proportion was 50%. The lower bound of the estimated confidence interval is above this. Hence, the hypothesis is accepted. It seems patients perceives it useful to gain online access to their health records.

## 7.1.2 Desired support for Use Cases

The participants were asked to rate how important they thought support of a given set of use cases were if they were to gain online access to their health records. The rating was on a scale from one to six, where one was “not important at all” and six was “very important”. An overview of the responses is given in Figure 7.2.

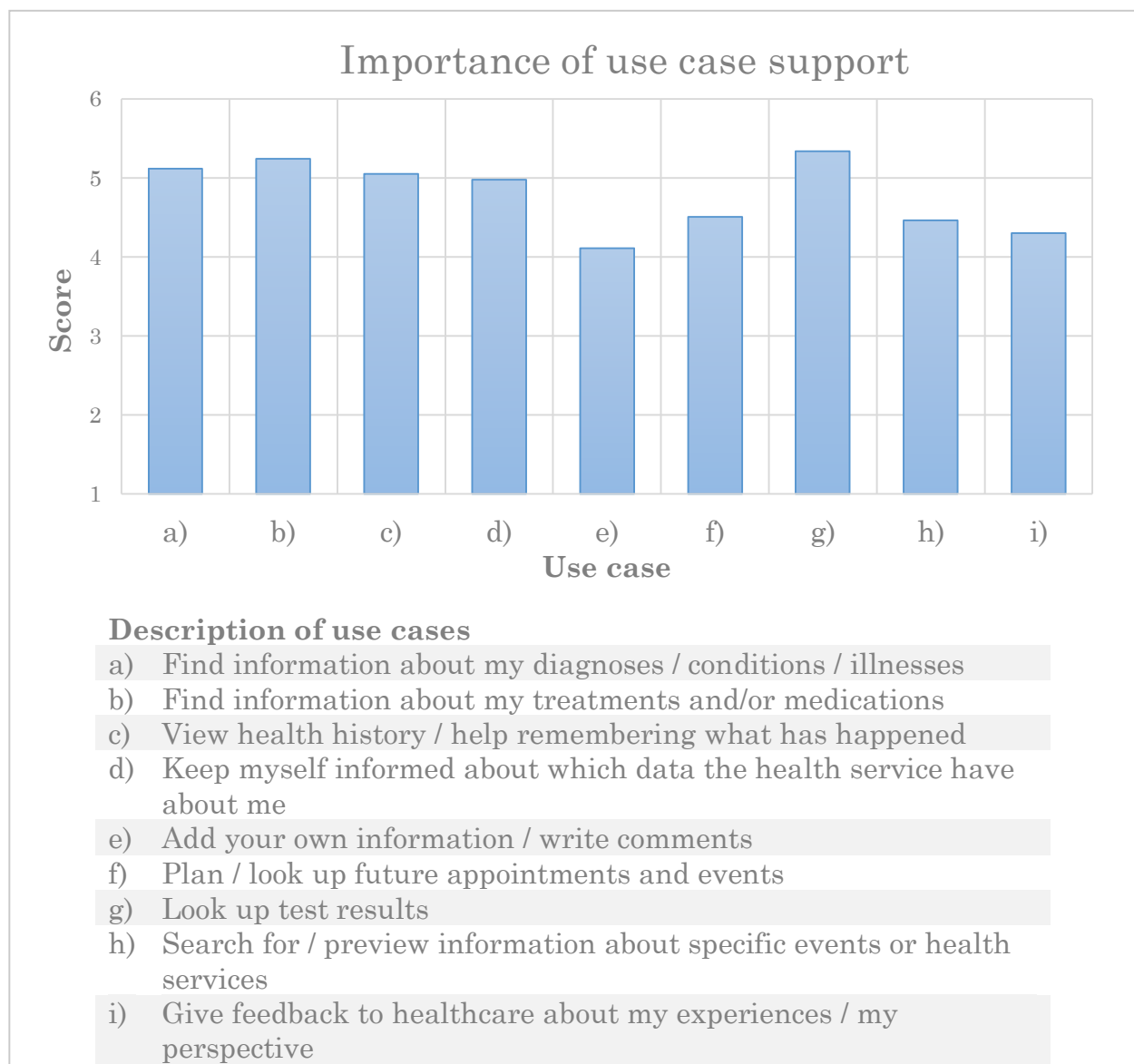


Figure 7.2: Chart of responses to importance of use case support.

The sample means, margin of errors and estimated population means are summarized below in Table 1.

Use cases	Sample mean	Margin of error	Estimated population mean <sup>27</sup>
a) Find information about my diagnoses / conditions / illnesses	5.12	0,23	4,89 - 5,35
b) Find information about my treatments and/or medications	5.24	0,21	5,04 - 5,45
c) View health history / help remembering what has happened	5.05	0,22	4,83 - 5,27
d) Keep myself informed about which data the health service have about me	4.98	0,27	4,71 - 5,25
e) Add my own information / write comments	4.11	0,29	3,82 - 4,40
f) Plan / look up future appointments and events	4.50	0,29	4,22 - 4,79
g) Look up test results	5.34	0,18	5,16 - 5,52
h) Search for / preview information about specific events or health services	4.47	0,27	4,20 - 4,73
i) Give feedback to healthcare about my experiences / my perspective	4.30	0,28	4,02 - 4,58

*Table 1: Table overview of the importance of use case support.*

These results suggest that support of all use cases are conceived to be important. The only use case that has an estimated lower bound below 4 is adding their own information / writing comments (e).

Generally, use cases that are related to retrieval of health information are rated higher than those related to feedback, supplementing information and prospective events.

The hypothesis (**H2**) was that patients considers it important to be able to use a system that provides them with their health record to achieve the given set of use cases. The corresponding null hypothesis stated that the estimated population mean of use cases ratings was four. All the use cases have an estimated population mean of at least four or above, except use case the use case (e) “adding their own information / write comments”.

<sup>27</sup> Estimated by calculating the 95% confidence intervals as described in section 5.2.5.1.2.

Thus, the hypothesis is accepted for all use cases, except for (e). However, the results indicate that (e) also may be considered important, at least for some patients.

Participants were also given the opportunity to supply additional desired use cases. The following use cases were suggested:

- 1) Get overview of vaccinations, recommended vaccinations, health services in residential area, prices on health services, prescriptions and dental records.
- 2) Get relevant / recommended links for illnesses
- 3) Get link(s) to online forum for people with similar conditions
- 4) Online communication/consultation with health practitioners
- 5) Set up appointments with GP
- 6) Order prescriptions

These suggestions indicate that participants are interested in simplifying communication with health care practitioners and retrieving health related information.

### 7.1.3 Importance of information

The participants were asked to rate how important they considered a set of given information for each event or health service. The rating was on a scale from one to six, where one was “Not important at all”, and six was “very important”.

Figure 7.3 gives an overview of the responses.

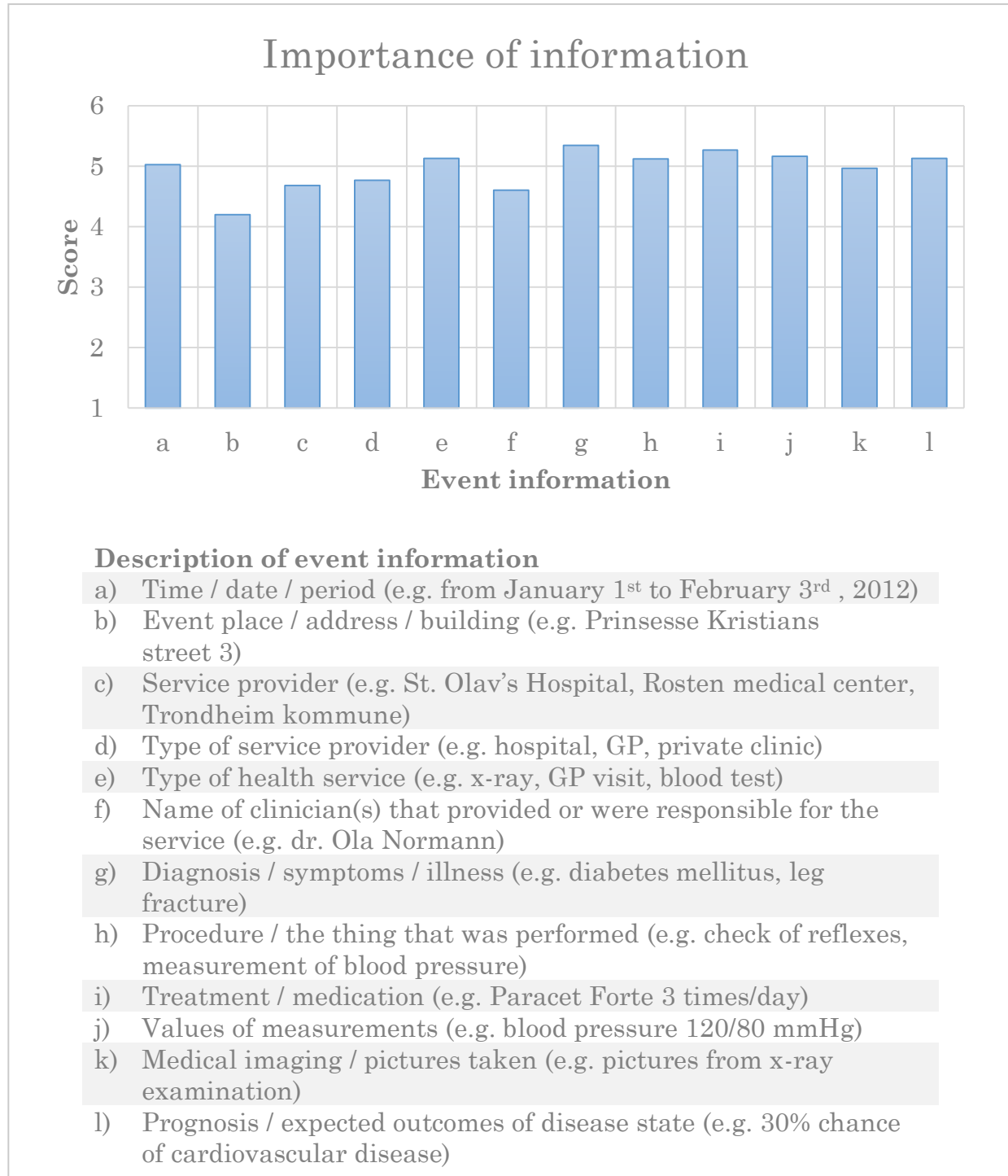


Figure 7.3: Chart of responses to importance of information.

The sample means, margin of errors and estimated population means of these results are summarized in Table 2 below.

Information <sup>28</sup>	Sample mean	Margin of error	Estimated population mean <sup>29</sup>
a) Time / date	5.02	0.24	4,78 - 5,26
b) Place / address	4.19	0.31	3,88 - 4,50
c) Service provider	4.68	0.25	4,43 - 4,93
d) Type of service provider	4.77	0.24	4,53 - 5,01
e) Type of health service	5.13	0.23	4,90 - 5,35
f) Name of responsible clinicians	4.60	0.26	4,34 - 4,86
g) Diagnosis	5.34	0.19	5,15 - 5,53
h) Procedure	5.12	0.22	4,89 - 5,34
i) Treatment	5.26	0.22	5,04 - 5,48
j) Value of measurements	5.16	0.23	4,93 - 5,38
k) Medical imaging	4.96	0.23	4,74 - 5,19
l) Prognosis	5.13	0.21	4,92 - 5,34

Table 2: Table overview of importance of information.

The hypothesis (**H3**) was that patients considers it important to have the given set of information presented about health services they have utilized. The corresponding null hypothesis stated that the estimated population mean of information ratings was four. All the use cases have an estimated population mean of at least four or above. Thus, the hypothesis is accepted for all types of information.

The responses are generally high, and the difference in rating is not always substantial. It becomes apparent that participants with some exceptions rate health related information higher than circumstantial information. However, these differences are too small to generalize.

<sup>28</sup> This is only a short description of the information; see Figure 7.3 for entire description.

<sup>29</sup> Estimated by calculating the 95% confidence intervals as described in section 5.2.5.1.2.



Just as in desired use cases, the participants could supply types of information they would like to have presented for health events or services. There were only one suggestion, and that was the cost of health service.

There were no mentioning in the comments or indications from the ratings that patients desire some information to be omitted.

These results suggests that patients find all the suggested information relevant.

### 7.1.4 Sharing of supplemented information

Participants were asked if they would consider sharing the information they themselves might submit to an online health record with researchers and/or clinicians. The results are summarized below in Figure 7.4.

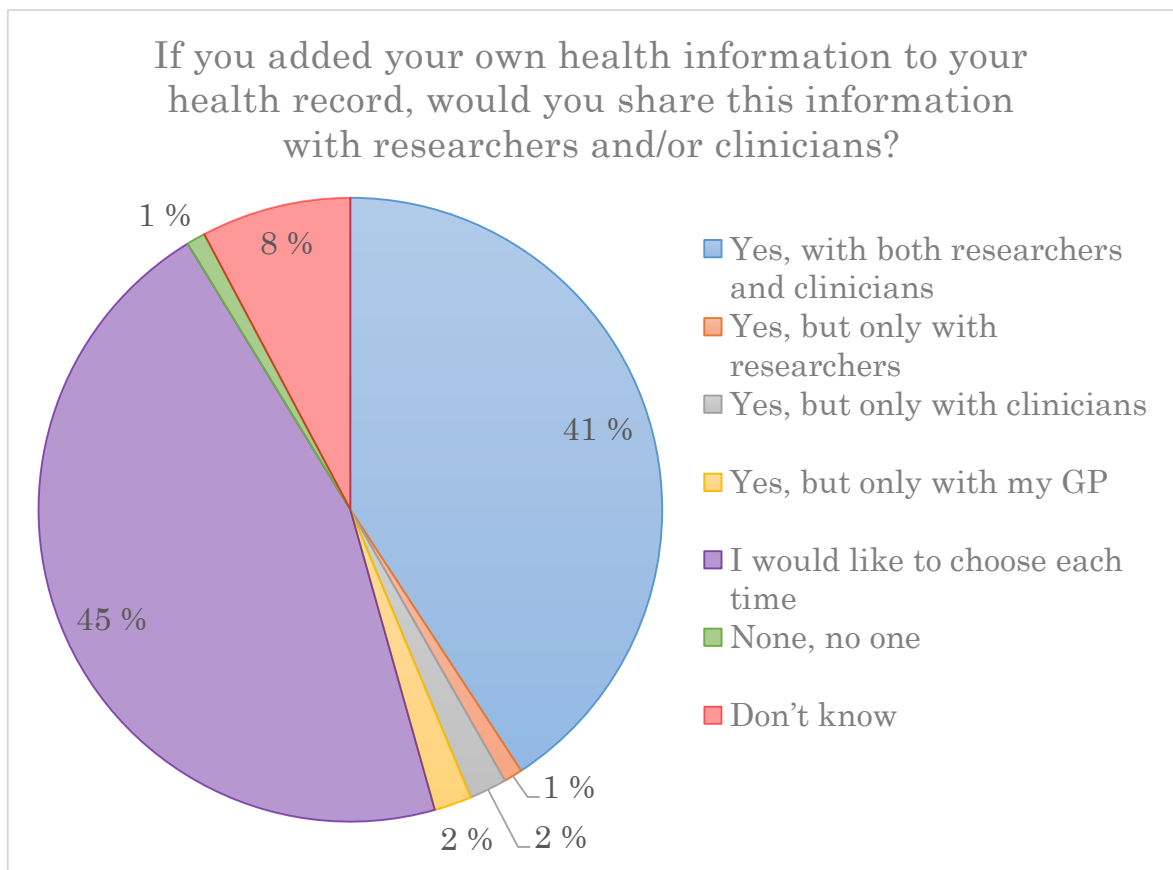


Figure 7.4: Chart of patients' responses to sharing supplemented information.

Most of the participants would either share all information with both researchers and clinicians, or choose each time with whom they would share the information. The participants who were positive to sharing all or some information with either researchers or clinicians constitute 91% of the participants.

Only one participant did not want to share any information, however eight were uncertain if they wanted to.

Those who wanted to share all information with either their GP, other clinicians, and/or researchers constitute 41% of the participants. By calculating the confidence interval, the population proportion is estimated to be between 41.5% and 50.5%. The population proportion of those who wanted to choose each time whom to share information with constitutes, is estimated to be between 35.39% and 54.61%.

In total, the population proportion that is positive to sharing all or some information is estimated to be above 77%. The hypothesis (**H4**) was that patients would like the opportunity to share their supplement data with researchers and clinicians. The corresponding null hypothesis was that the estimated population proportion was 50%. Hence, the hypothesis is accepted. The results suggests patients are very open to the idea of sharing input with healthcare and health researchers.

### **7.1.5 Comments from participants**

13 participants submitted additional comments at the end of the questionnaire. Out of these, 12 were about the desire to gain online access health records. Two of these also stressed the importance privacy, security, and patients themselves being able to control insight.

The last comment was from a participant that commented that she did not think patients should search in symptoms and do self-assessment/self-diagnostics on such Web sites. Nevertheless, she thought it would benefit herself to gain online access to her health record.

## **7.2 Test of Functional Appropriateness and Usability**

This section states the results from the test of functional appropriateness and usability. 10 people participated in the test in individual sessions which lasted about 30 minutes each.

### **7.2.1 Digest of observations and comments during user tasks**

The think-aloud method was mostly well adopted by the participants. Some participants emphasized what they were doing more than what they were thinking. However, if some parts were inadequately commented during the user tasks, these parts were noted and brought up during the retrospective interview.

Although the participants were informed that they themselves were to choose how they solved tasks, a few were confused by the tasks not being worded in a way that was directly associated with a function in the user interface. If this stopped the execution of tasks, they were reassured that they themselves choose which functions to use.

#### **7.2.1.1 PHR utilizing EHR visualization (EPHVis)**

All participants quickly oriented themselves in the timeline from the very start of the user tasks. Several of them began the test with commenting that they were seeing a timeline and that it was easy to understand.

Commonly, at the start of the test, the participants started by orienting themselves in the y-axis, which initially was set to group events by service provider, and then orient themselves in the x-axis. This familiarization was done in a matter of a few seconds. When the participants had oriented themselves once, they usually took advantage of the fact that events were placed chronologically on the timeline, and the x-axis was only gazed upon occasionally when they were looking for specific times. Hence, when looking for the first or last event at some service provider, they started by looking in the y-axis, and proceed to inspect the events that were placed where they thought the event they were looking for would be. The y-axis worked as a starting point throughout the tasks. None of the participants had problems understanding that events were grouped in lanes that initially were affiliated with service provider.

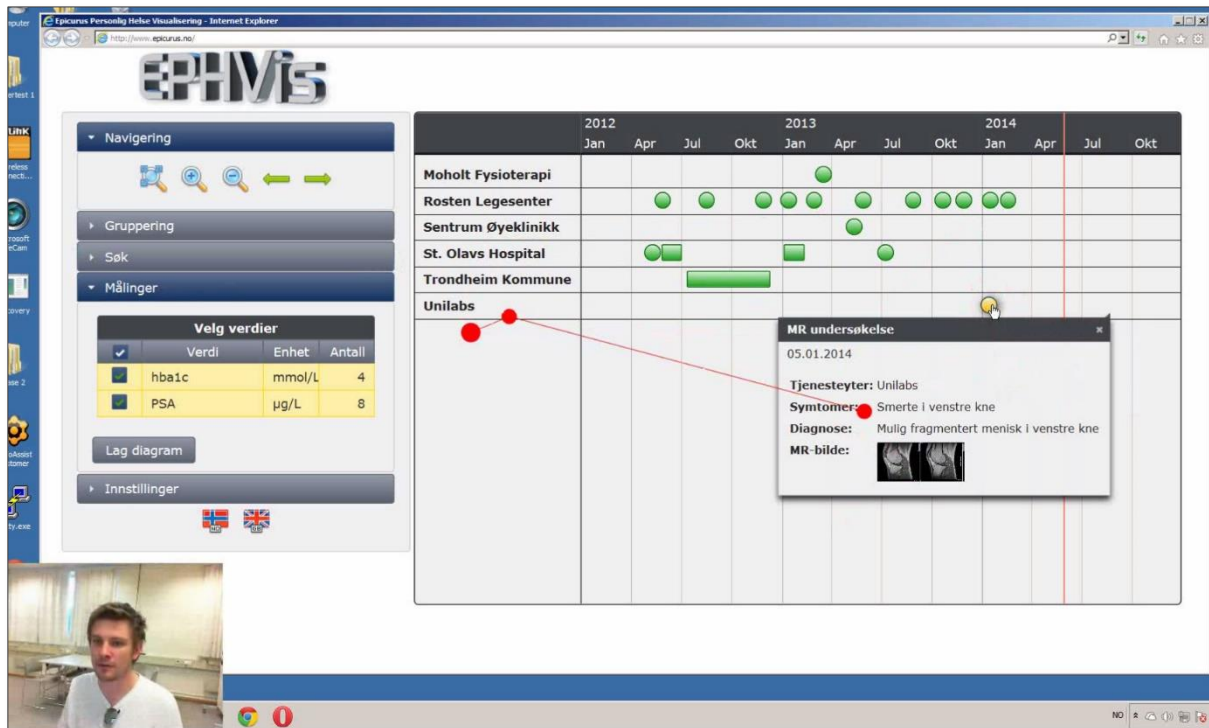


Figure 7.5: Test of EPHVis. The red dots with the red line in-between visualize where the user was looking. The size of the dot indicates how long the point was in focus.

Although the tasks mentioned that the participants should “click on the event”, many participants did not read this before starting to execute the first task. Some reported after doing the first tasks that they had though the steps below the goal was secondary objectives that they were to be executed after the main goal was finished. Nevertheless, it seemed intuitive to them that they could get on-demand detail by clicking on the events in the timeline.

Generally, the participants spent very little time finding events. Everyone either went straight to the correct event, or assessed 2-3 events in an estimated area before finding it. Some used this technique exclusively to find events throughout the test, while others utilized the grouping and search functions. Several participants reported that they would have used the search and grouping functionality more if the health record had been more complex.

When asked to find a hospitalization, most of the participants went almost directly to the first rectangular event. However, a couple of them did not seem to differentiate between events that took place at a specific point of time, which were represented as dots on the timeline, and those that took place over a period of time, which were represented by rectangles. These were asked in the retrospective interview what they thought these meant, and both had understood the difference. Therefore, it is not clear if this was caused by them not interpreting “hospitalization” to be something that was over a period of time, or

if they did not reflect upon the difference at when executing the tasks. However, it may indicate that point and interval events should be more visually different.

One of the tasks asked the participants to find the last routine checkup affiliated with Diabetes. These checkups were affiliated with two different service providers. This challenged the initial y-axis grouping, as they needed to find an event by some description that was not explicitly given in the overview, i.e. it was not given where this event was in the visualization. Two functions would optimize the process of finding the event: 1) By grouping event by disease affiliation, which switched the y-axis lanes to diseases, or 2) by querying the search function with “diabetes” or something similar. Two participants found the event by changing the y-axis grouping, and both of them expressed satisfaction with this function. The rest of the participants assessed which of the service providers that had the last events, and inspected these to find the last checkup affiliated with Diabetes. All of them seemed confident about what they were doing, and everyone found the correct event.

All participants reported that they were very pleased with the fact that they could build a diagram with one and several measurements that showed the values over time. Several though this would be one of the functions they themselves find very useful to have.

All participants were able to achieve the correct goals in the tasks, but some struggled more than others did. Most problems were caused by misinterpreting or misreading of the task text. When this happened, they were then asked to read the text more carefully. They were then able to perform the task properly.

### 7.2.1.2 PHR in tabular form (HMU)

The participants that tested the tabular form PHR, called HMU, commonly started their test familiarizing themselves with the columns in the overview. Some of them struggled to gain overview and did not understand that they could retrieve additional information by clicking the rows. One participant did not initially realize that each row represented an event and commented, “I’m trying to find my way, but things seems to be a little messy here”.

Some also mentioned being confused by the terms used in the column headings, especially “service unit” and “specialist unit/specialty”<sup>30</sup>. The sparse information in the “service unit” column was misinterpreted by one participant, who though that a blank field meant it was the same as the one above (e.g. if one row read “cancer clinic” and the one below was blank, the participant interpreted this event to also belonged to the service unit “cancer clinic”).

When looking for events, the technique that was mostly used was to start at the top of the list and inspects every event until they found the correct one. Some

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<sup>30</sup> Translated from “Tjenesteenhet” and “fagenhet/spesialitet” respectively. These were purposely sparse in order to assess how the user interface handled heterogeneous or uncompleted data.

took advantage of the fact that the list initially was chronologically sorted and started at the bottom of the list when looking for recent events. One participant was confused by the fact that the oldest event was at the top, and said that it ought to be reversed so the newest came first. None of the other participants mentioned or seemed confused by the initial sorting. In fact, it seemed intuitive to them that the oldest was placed first; all of them immediately started looking at the events in the top of the list when they were asked to find the first hospitalization at St. Olav's in task 1.

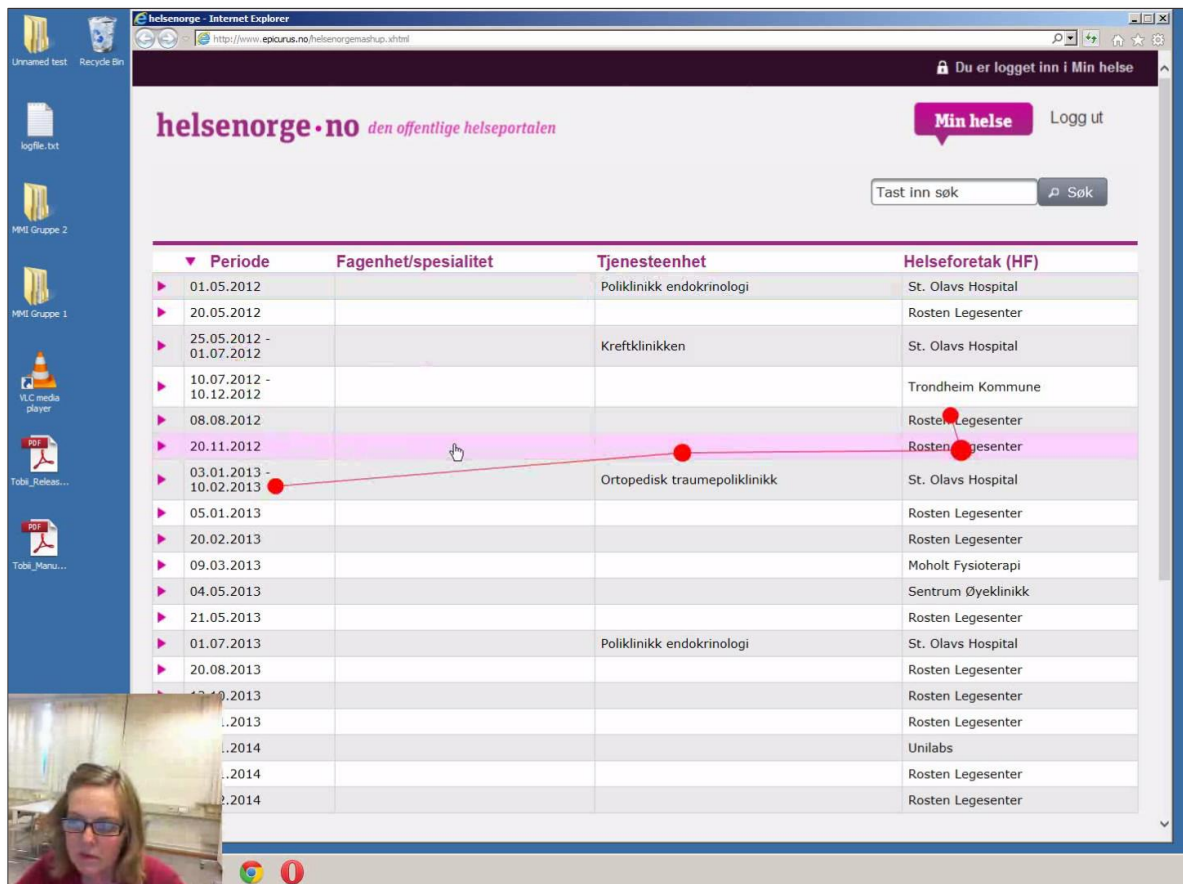


Figure 7.6: Test of HMU. The red dots with the red line in-between visualize where the user was looking. The size of the dot indicates how long the point was in focus.

Only one participant specifically looked for events that were over a period of time when looking for the hospitalization in task 1. The rest systematically clicked through events until they found the hospitalization.

When the participants proceeded to find event by content or affiliation with a disease, most were very unsure what to do. Several went systematically through all events from the top, and commented that the process was troublesome and overwhelming. Of those who used the search function during the test, most utilized it at first when they were to find the last checkup affiliated with diabetes in task 3. All of them reported that they were pleased with the function, and

most of them used search exclusively to find events in latter tasks. The events that resulted from a search were sorted by hit rate on the query, and not by time. This confused several participants and they had to be helped to get the events sorted chronologically again.

In task 4, the participants were urged to gain an overview of the hba1c and PSA tests that had been taken. All except one participant looked for a function that gives this exclusively. Some commented that the way they were asked to do the task was ambiguous, and requested a graph or table for measurements. After realizing that there was no specific function for abstracting measurements, some participants proceeded to use search while others went systematically through all events.

As a positive consequence of the systematic manner of going through events, most participants remembered the MRI examination they were asked to find in the last task. Hence, they went straight to the event.

## 7.2.2 Retrospective interview

After the user tasks were executed, the screen was turned off for the first part of the interview.

### 7.2.2.1 Overview and comprehension of dataset

At the start of this part of the interview participants were asked to think back about what had happened to Per, and they were asked a series of questions (listed in section 5.3.4.5) about Per's health data. In addition, they were encouraged to state how confident they were in each of their answers.

The overview and comprehension of the data varied slightly between the participants. This was natural as some participants were more thorough than others. However, some differences between the two systems emerged.

With regards to the overview of items that were explicitly addressed in the tasks, there were little difference between the group of participants that tested EPHVis and the group that tested HMU. However, regarding implicit information (i.e. information that were not directly addressed in the tasks, but were available in the presentation) the group that tested EPHVis seemed to have a better overview.

The participants had worked with three service providers in the tasks, while there were actually six in the example data. The group that tested the EPHVis application all knew the approximate number of service providers; all responded that there were five or six. The group that tested HMU had only counted the three that they had reviewed through the tasks. Despite this, there were no difference in how many names of service providers they remembered; common for both groups was that they remembered those described in the tasks.

The participants were asked if there had been any other hospitalizations at St. Olav's Hospital after the one they had assessed in task 1. While everybody in the group that tested HMU reported that they did not think so, or did not know, most of the participants that tested EPHVis reported that they were quite sure that there had been one. Two of them mentioned that they knew this because they had "seen a box" in the lane affiliated with St. Olav. In addition, three of the participants that had tested EPHVis were able to pinpoint the time of this event to the correct year.

When participants were asked to estimate the frequency of visits to Rosten medical center, the group that tested EPHVis estimated the number of visits to be lower than the other group. The estimates were slightly off in both groups, however, some of the participants in the EPHVis group described that the frequency had changed from being low in 2012, and higher towards the end between 2013 and 2014, which was correct. No one in the other group made similar remarks.

### **7.2.2.2 Feedback on EPHVis**

Although the phrasing were slightly different, all the participants that tested EPHVis reported that they thought the overall system was very easy to use, understand and navigate. They thought it was easy to orient themselves in the timeline and everyone reported that they found the difference in point and interval events helpful. Some mentioned that the timeline made it easy to see the time perspective, and get a sense of frequency and duration of events.

Several of them reported that they thought it was intuitive and convenient that they could click on events to get details about it. However, there were some issues with the content in the details. Firstly, many wanted the system to provide explanations or links to explanations of the medical terms; this was considered especially important when, as in the test, someone was helping another person. The detailed data in the test was not very extensive, so some mentioned they would like a little more details about each event, such as a short description of why the event took place.

Most of the participants that tested EPHVis did not report anything that caused confusion or difficulties in executing the tasks. Some negative feedback was given, asking to make things in the interface more visually pleasing (buttons, color, fonts and such). However, everyone emphasized that this was just a personal preference and would not really help their understanding or help them in achieving their goals. The only exception to this was that a participant reported that he was confused about the temporal granularity on the timeline. The intervals on every time unit on the timeline was initially every three months, however when he read "Jan" on the timeline, he thought all events in that unit was in January, even if an event actually was in February or March. Nevertheless, since the date also was given in the details box, this confusion was quickly resolved.



When asked how they would feel about having their own health data presented this way, the response was very positive. Most of them thought this was an excellent way of presenting health data and that it would make it much easier for them to remember and keep themselves informed.

Everyone was very satisfied with being able to change the grouping of events by disease affiliation instead of service providers. In fact, a few of the participants requested this function just before they found it in the interface. The graph function was also considered a very valuable and beneficial function. They also liked that they were able to combine several measurements into the same graph. Some of the participants wanted an additional indicator of what the measurement values meant, i.e. if they were high, low or in the middle of what it should be.

Most frequent comment as “the next step” was to include the application as a part of a more complete web site, which contained an introduction page with the possibility to do other things as well, such as updating prescriptions.

### **7.2.2.3 Feedback on HMU**

The feedback on HMU was initially positive, although they were much more restraint in their statements. Overall, all participants thought the system was satisfactory, easy to use and easy to understand. Terms such as “fine” and “okay” were often used to describe the system as a whole, and many described it as basic or simplistic.

However, everyone also gave negative feedback. Without exception, each participant had issues about the overview presentation. Several participants thought the columns should be extended or changed. Most wanted to keep the “period” and “service provider” columns, but said that the others had little or no value. Even if the columns had been complete with data; they considered it more important to know what the event contained or which diagnosis it was affiliated with. Some also found it confusing that some cells did not contain any data in the overview.

One participant thought it was impractical that only one event could be inspected at a time and drew an analogy to keyhole-peeping; he could only inspect one event at a time, so if he wanted to gain an overview of narrative, or correlation between something, he would have to copy the data to a spread sheet or something similar.

Many participants wanted the test results to be available separately so that they could gain a better overview of periodical measurements. In this context, several participants requested graphs for previewing test results.

Even though the example dataset only contained 19 events, several participants also saw the amount of information on-screen in the overview as a problem. Two

described it as an “overflow of information”. One participant suggested that the overview could divide events into smaller groups by month or year.

Search was the thing most participants mentioned as the thing they thought was especially easy. Two reported that they had lost oversight of the events when they received search results not sorted by time. They wanted the sorting by time to remain, instead of sorting results by hit rate.

Despite some negative feedback, all participants were positive to getting their health data presented in this way. Many justified this by saying that it was much better than the current solution were they had to ask their GP.

### 7.2.3 SUS scores

The SUS scores seem to be quite similar between the prototypes. The mean score of those who tested EPHVis was 92 points, and the mean score of those who tested MHU was 81.5 points<sup>31</sup>.

### 7.2.4 Functional appropriateness

In this section, the results from the test are summarized in the perspective of functional appropriateness, i.e. degree to which the functions facilitate the accomplishment of specified tasks and objectives.

The participants that tested EPHVis spent less time executing the tasks, had to inspect far less events in the tasks than the participants that tested HMU, and had a better overview of the dataset. This result indicate that the visualization provides an overview of the dataset that is not gained through a tabular presentation as in HMU. In addition, the participants that tested EPHVis experienced less difficulties and problems tied to the representation than the group that tested HMU. Only one problem emerged that may cause problems when retrieving health information from the system, and that was the issue of temporal granularity and units’ textual representation on the timeline. This was though a minor problem for the one participant that was confused by it, and can easily be fixed by changing the granularity to months, or changing the text so that it gives a better description of what it represents. However, those who tested HMU had several issues with gaining overview, inability to preview narrative and correlation, and overflow of information. This is all issues that inhibits information retrieval. Hence, the results suggests that visualizing health data to patients as a timeline of events is more functional appropriate than presenting them in a tabular form.

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<sup>31</sup> It should be noted that one of the participants that tested MHU scored it to a 100 points, but at the same time expressed in the retrospective interview that it was not completely satisfactory.

## 7.2.5 Usability

In this section the results from the test are summarized in the perspective of usability, i.e. the degree to which a product or system can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use<sup>32</sup>.

Both ways of presenting health data to patients seem to be usable. Despite their issues, all participants, regardless of which system they tested, though it was easy to use and understand. They also reported that they would find it satisfactory to get their own health data represented in the way they tested.

### 7.2.5.1 Effectiveness

Participants used different approaches, but everybody, regardless of system, were able to achieve the goals given in the tasks. Their execution differed in accuracy, but this was often linked to how thorough they were in their execution.

### 7.2.5.2 Efficiency

The approach the participants took was quite different. Those who tested EPHVis mostly found data by looking at the service providers first (the y-axis), and then estimating roughly where the event would be. Mostly they found their event amongst the first three they inspected. Those who tested HMU followed a much more structured approach where they started at the top or bottom of the list, and inspected each event until they found the one they were looking for.

Participants that tested EPHVis were substantially quicker in their execution of tasks than those who tested HMU. However, the number of participants is too low to conclude if the difference is significant.

### 7.2.5.3 Satisfaction

The feedback was more negative for HMU than for EPHVis in the retrospective interview. However, the participants were mostly satisfied with both systems. When asked about their satisfaction with the prototypes, many participants were more concerned with the information they could potentially retrieve from an online health record than how this information was presented to them. The SUS scores showed little difference in satisfaction between the groups, although EPHVis scored slightly higher. Some patients seemed to be more generous in the SUS scores than they were in the retrospective interview, especially those who expressed strongly that they personally were in need of gaining online access to their health record.

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<sup>32</sup> ISO/IEC 25010

## 7.3 Visualization feasibility analysis

This section states the results of the analysis of large scale-usage in the PAsTAs online questionnaire of information visualization techniques derived from state-of-the-art EHR visualization. As of writing, 1426 people have participated in the online questionnaire<sup>33</sup>.

### 7.3.1 Drop in number of participants caused by visualization

The first thing that was investigated in order to estimate the drop in number of participants throughout the questionnaire was the number of stepwise submissions. As mentioned in the description of the method in chapter 5, the stepwise submissions are the number of times the participants have pressed “forwards” and thereof submitted their answers to a step.

Figure 7.7 gives an overview of the number of stepwise submissions participants submitted during the survey. The x-axis gives the number of stepwise submissions and the y-axis gives the number of participants. The blue columns represent the participants with incomplete responses, i.e. the participants that did not finish the questionnaire, and the orange columns represent all participants. The table below the chart gives the number of participants for each number of stepwise submissions.

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<sup>33</sup> This number does not include those who have participated on paper.

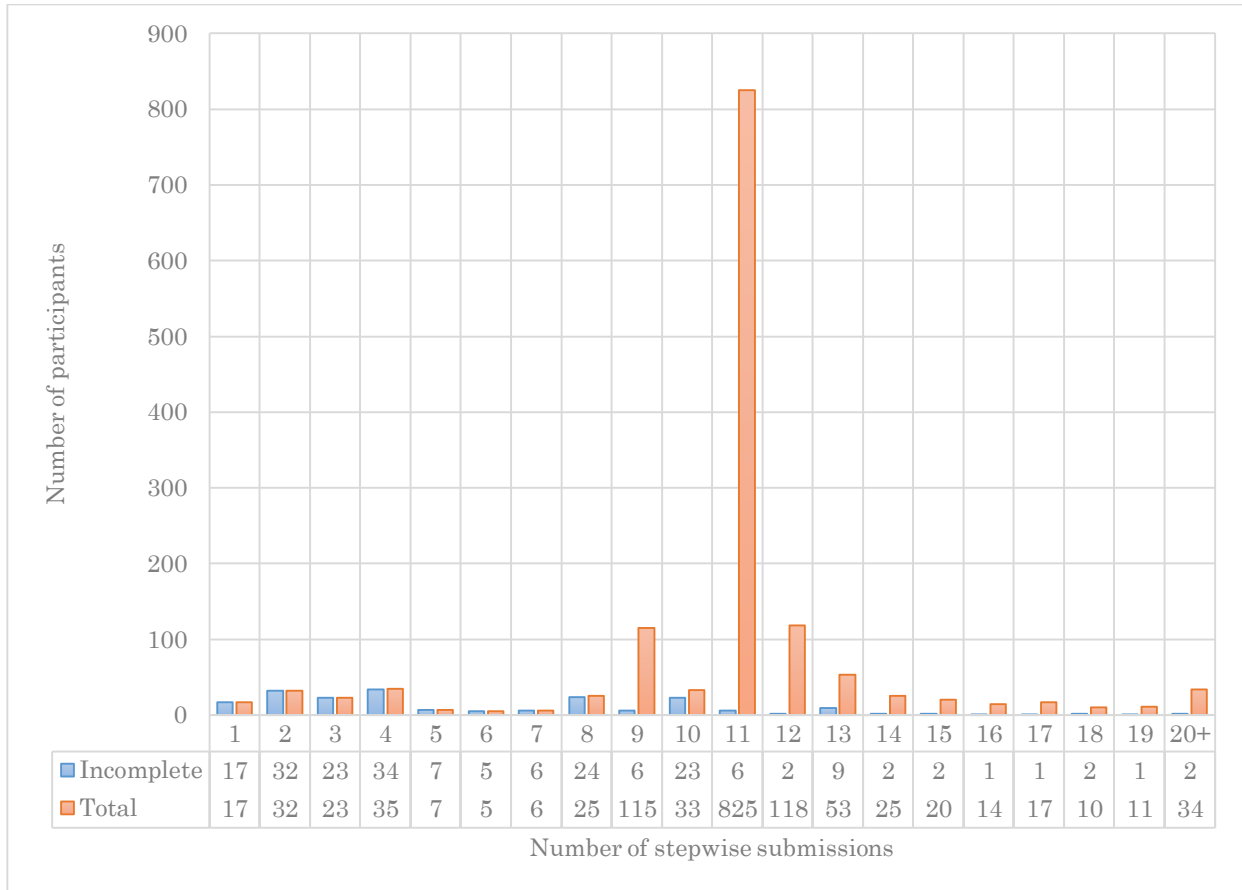


Figure 7.7: Chart of stepwise submissions of participants.

Out of all participants, including those who finished the questionnaire, most committed 11 submissions, one for each step. Since two steps were conditional (step 7 and 8) on certain answers on earlier steps, many participants also finished the survey in 9 steps. This suggests that most participants used little or no backwards traversing. However, several participants also exceeded the number of submissions needed to finish the survey. This indicates that backward traversing was utilized to some degree, but people accessing the online questionnaire several times may also have contributed to these numbers.

Of the respondents that did not finish the questionnaire, most left after committing 1, 2, 3, 4, 8 or 10 steps. Those who left without finishing after 10 or more steps are likely to have experienced technical difficulties that prevented them from completing. Indeed several such complaints were registered by support.

The visualization was first included in step 4. Considering that participants generally only utilize forward traversing, participants leaving the questionnaire due to the visualization would likely result in three stepwise submissions (i.e. they did not continue from step 4). As apparent in Figure 7.7, under 2% of all participants left the questionnaire after submitting three steps, thus most likely leaving on step 4. This dropout rate is slightly lower than the surrounding steps

(2 and 4), and is not substantially higher than other steps (cf. 1, 2, 4, 8 and 10). This suggests that the visualization did not make users leave the questionnaire.

The number of stepwise submissions could be affected by the backwards traversing, since a step backwards would result in an extra submission of a previously committed step when the user continues forwards again. In addition, the number of stepwise submissions does not determine actual participation; submissions may simply be a result of users browsing through the questionnaire. Therefore, in order to improve the estimate of how many left the questionnaire, the number of known participants, based on the number of answers to each question, was analyzed. An overview of the findings is given in Figure 7.8.

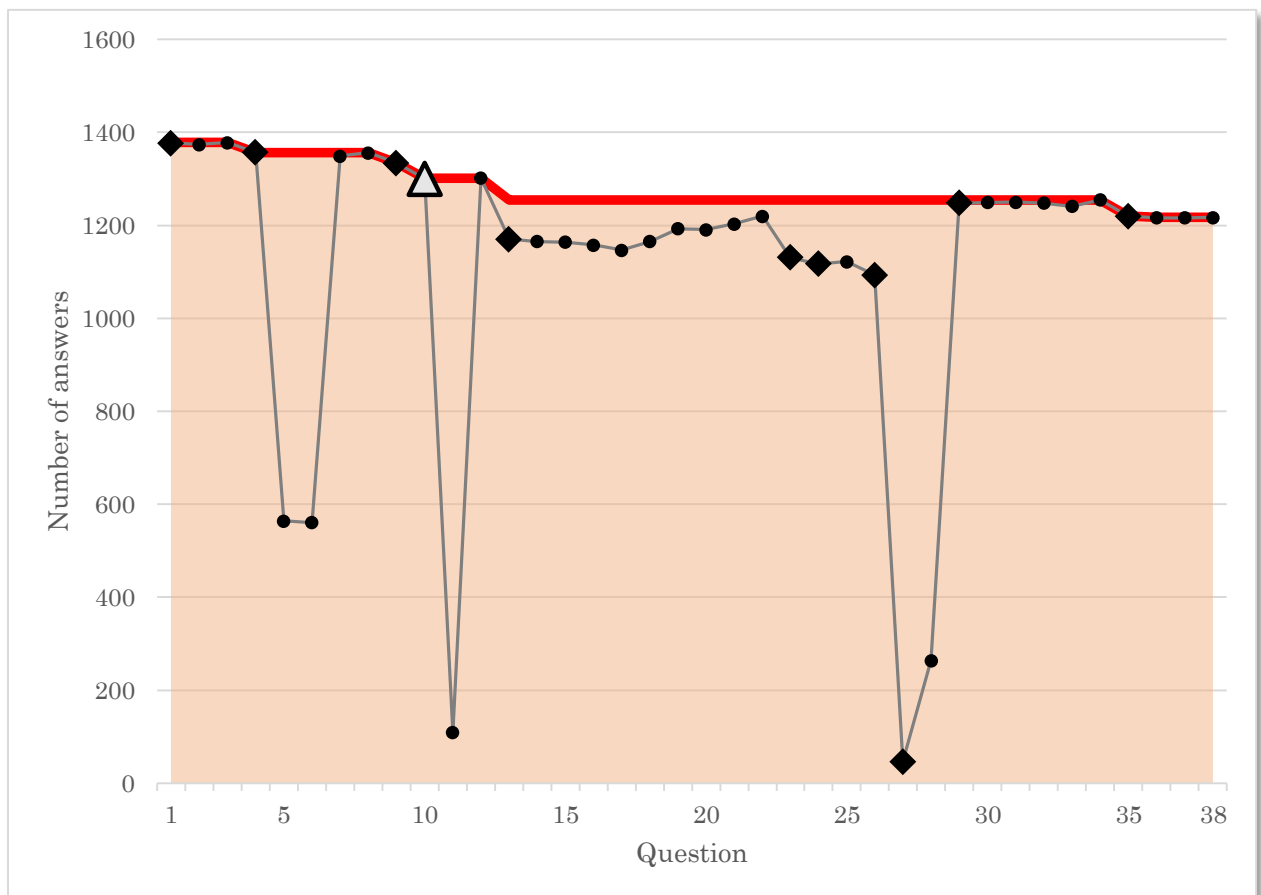


Figure 7.8: Chart of question participation and known number of participants.

The chart shows the number of participants on each question and known participants at any given time in the questionnaire. The y-axis gives the number of participants. The x-axis gives the question number (the survey progresses from left to right on the x-axis); in total there were 38 questions. The red line and the beige background gives the known number of participants, regardless of their participation on individual questions. The tilted squares represents the questions that were at the start of a new step (in total 11). The black and gray triangle represent the start of step 4, where the visualization was first included.

The black circles are the other questions in the survey. A gray line links all questions in order to make it easier to see the progression in the questionnaire.

As mentioned, the participants were first presented with the visualization together with the question asking if the presentation was correct, at the start of step 4 (gray triangle in Figure 7.8). At the end of step 3, just before the visualization was included, there were 1316 known participants. This dropped with 14 participants on the first question after the visualization, on the start of step 4. This is a drop of 1%. The overall drop in known participants throughout the entire questionnaire was 12%. As the questions were divided into 11 steps, the average drop on each step was slightly above 1%.

Question number 5 and 6 in the second step, number 11 in the fourth step and number 27 and 28 in the ninth step were conditional and thus had significantly fewer participants than the surrounding questions. This can be seen by the large downwards spikes on the gray line in Figure 7.8.

Through step number 5 to 9, the participation on questions were lower than in later steps (number 10 and 11). This caused the number of known participants to go down abruptly by 3% on step 5 (as apparent by the red line in Figure 7.8). However, it is not certain that they left at step 5; some participants may have terminated the questionnaire on a later step, towards step number 10.

Considering the above and the fact that that the drop of participants from the third step to the fourth step is slightly below average, one cannot conclude that the drop of under 2% from the number of stepwise submissions and 1% in known participants is substantial enough to be caused by the introduction of the EHR data visualization. Hence, the results suggests that the visualization was feasible for most users.

### 7.3.2 Responses from participants when asked if the presentation was correct

As described in the method chapter, the first question after the visualization was introduced in the questionnaire asked if the presentation of the participant's health service usage was correct. This was a multiple-choice question, where participants could answer with one out of five answer options. An overview of the responses is given below in Figure 7.9.

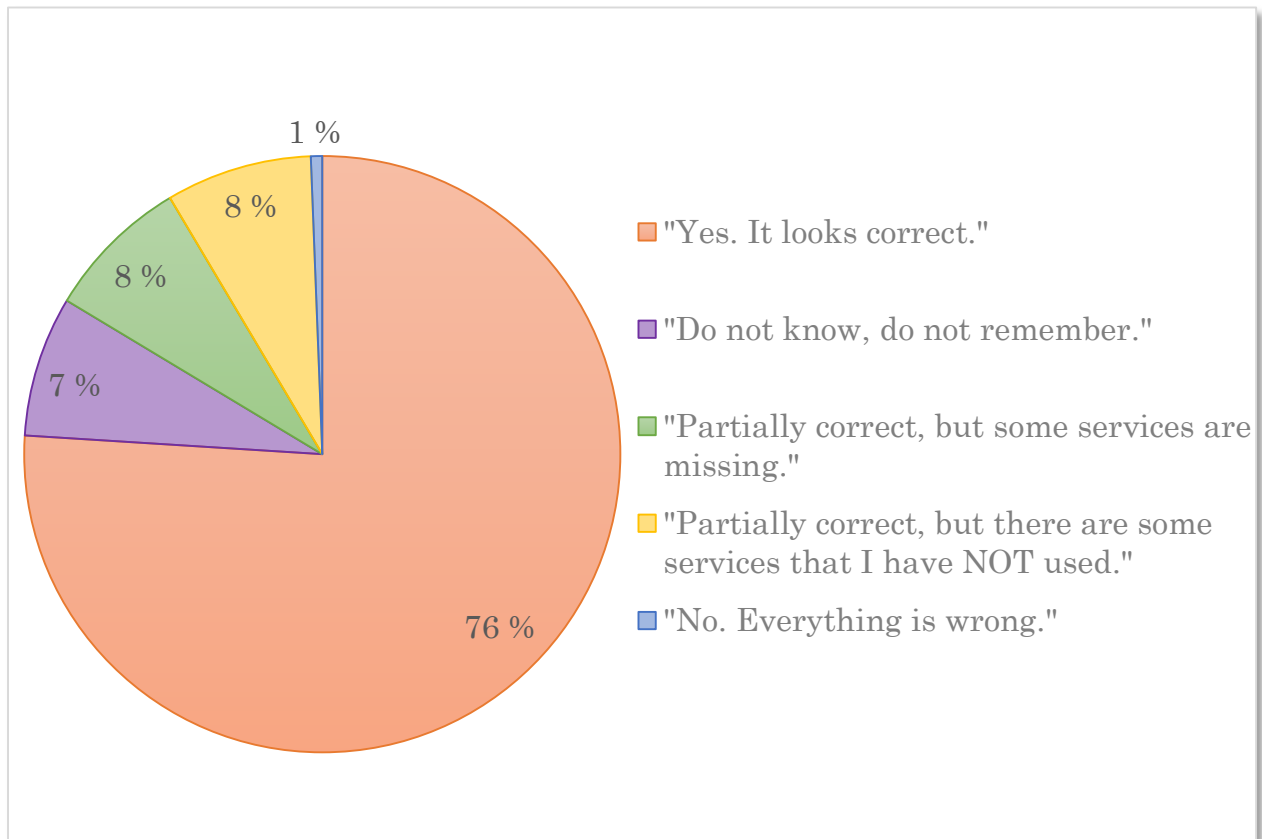


Figure 7.9: Chart of correctness of health service usage presentation.

Out of the 1300 that answered this question, 988 (76%) of them reported that it was indeed correct. Additionally 102 participants (8%) reported that the visualization was partially correct, but some services were missing. Participants should be presented with their own health data and therefore it should be correct, however, the health data used in the survey were only gathered from some healthcare organizations, and thereby may not be complete. Participants should select one of these two answer options if everything when as planned, and therefore it is probable that those who responded with these answers understood and had correctly interpreted the visualization they were presented with. Together, the group that responded with these answers constituted 84% of the participants.



99 participants (8%) reported that they “do not know, do not remember”, 103 participants (8%) reported that it was partially correct, but there were some services that they have not used, and only eight participants (<1%) reported that everything was wrong. These three differ from the first two, as they should not happen.

It is possible that some of the responses with these three answers were a result of participants misunderstanding, or misinterpreting, the visualization. However, it could also be a result of poor memory, errors in the dataset or errors in the merging of various data sources.

If we assume that the participants that did not *understand* the visualization, and realized so, all responded with “do not know, do not remember”, one can argue that this group constitute a maximum of 8% of the participants.

# 8 Discussion

In this chapter, the methods and findings are discussed. The first section discuss the credibility of each individual research method. Thereafter, a more general discussion follows of the results in consideration to the project's research questions and their meaning, influence and implications. Finally, the limitations of this research is discussed.

## 8.1 Credibility

This section discusses the credibility of the research that has been done in this project. Mainly this discussion concentrates on aspects of the research that should be considered when interpreting the results, and how representative these results are in general.

### 8.1.1 Credibility of the online questionnaire

This section discusses the credibility of the results from the questionnaire survey. Especially in consideration to representativeness for the general population.

#### 8.1.1.1 Representativeness for population

The total population in Norway is approximately five million. With a confidence level of 95%, a random sample of 100 people suggests a margin of error around 10%<sup>34</sup>. However, this is only valid if the sample is random, i.e. each person in the population has equal chance of being sampled. As the selection was restricted to the Trondheim area, the results can only be representative for this group. Invitations were distributed randomly by mail in most residential areas in Trondheim. Of the approximately 800 invitations that were distributed, 13% participated. Since participation was voluntary and on a limited sample, voluntary response bias, nonresponse bias and under coverage may affect the results.

##### *8.1.1.1.1 Voluntary response and Nonresponse bias*

Voluntary response bias arises when the sampling process in a survey is voluntary and because of this attract people with strong opinions about the subject of interest that does not comply with the opinions of the general

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<sup>34</sup> The margin of error varies, as it is dependent on the responses.

population. This causes the group to be overrepresented in the survey results, and therefore push the results in a certain direction.

Nonresponse bias arises when those who decline the invitation to participate affect the results. If these people constitutes its own group in the population, and this group does not partake, it will not be represented in the survey results. For example, people that are very busy may be more likely to decline an invitation to a voluntary survey.

These considerations also apply to the survey in this project. It is possible that those who took the time to respond to the survey was more interested in gaining online access to their health record than the general population. It is also possible that people that had little interest choose to decline the invitation. This is especially important to consider for the questions of perceived usefulness of gaining online access to health record.

In aspect to importance of use case support, information about health events and willingness to share their own supplemented data, this voluntary and nonresponse bias may have a positive effect. These questions maps the patients' perspective on such a system. The perspectives of those who have no interest in a system that provides online access to health record would not yield valuable insight.

The optional contest was advertised in the invitations to encourage participation. As a secondary effect, this advertisement gives a motivation for participation that is not tied to their opinion on the subject of interest. Thus, it is likely to have reduced the amount of voluntary response and nonresponse bias towards online access to health records.

Moreover, the survey was not publicly advertised, but a selection of people was invited. It is probable that this contributed to reducing the voluntary bias, as this limits the number of people that may have strong opinions on the subject of interest.

#### ***8.1.1.1.2 Under coverage***

Under coverage occurs when a group in the general population is not represented in the sample. As this was an online questionnaire, one group that cannot be represented is residents without a computer or Internet access.

As this was a voluntary anonymous survey, it is hard to identify groups that might not have been represented. From the demographic information that was collected about participants, it seems that the participants are fairly heterogeneous, spanning in age, education, life and health situation. However, there are a couple of indications from the demographic data that needs to be considered.

Of the 103 participants only one participant claimed to be a “novice” on the computer, and most of the participants used the Internet on a daily basis.

Therefore it seems that the survey might suffer from an under coverage of people with poor computer literacy. This was expected, as the survey was online.

In addition, only two participants had no education above primary school, only one participant was unemployed and none of the participants was homemakers. Thus, these groups seem not to be adequately represented in the sample.

### **8.1.1.2 Duplicates and spam**

Since the questionnaire survey was done online, there is a chance that the survey was exposed to spam or duplicates from participants submitting their answers more than once. Without a permit from the Norwegian Social Science Data Services (NSD), which is NTNU's data protection official for research<sup>35</sup>, the law in Norway prevents coupling the survey responses with IP-addresses or other information that could identify respondents. This makes it troublesome to determine and remove spam and duplicates.

In order to partake in the voluntary competition, participants needed to enter their phone number. These phone numbers were kept in an independent secondary data store, to ensure that this data could not be used to identify which responses a participant had submitted.

Phone numbers were deliberately chosen as the competition contact information, over e.g. e-mail, because they are difficult to obtain in large quantities. Phone numbers are usually personal, or at least affiliated with a small number of people, thus people entering the optional competition helped facilitate accuracy of the survey and gave some indication of the possible amount of duplications and spam. Any attempts to enter a phone number more than once, would invalidate the survey submission and result in an error message. Additionally, the application logged all such occurrences. This obstructed attempts of flooding the secondary data store to increase winning chances. An examination of the secondary store shows that 85 of 103 participants entered the competition. It is therefore probable that at least 85 participants were genuine and unique.

In addition, a post-survey search for equal responses was performed to determine if some responses were duplicates, i.e. contained exactly the same data. This was done because as it is unlikely that two or more participants entered exactly the same information<sup>36</sup>. No duplicates were found in the survey responses.

## **8.1.2 Credibility of the test of functional appropriateness and usability**

This test was a qualitative assessment of functional appropriateness and usability done on 10 participants. This sort of qualitative tests cannot *prove* that

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<sup>35</sup> <http://www.nsd.uib.no/personvern/en>

<sup>36</sup> There were well over 10 quadrillion ( $10^{15}$ ) possible answers to the questionnaire.

one approach of presenting health records to patients is more functionally appropriate and/or usable than another. However, the test can on the bases of the observations and participants' statements, *assess* the different approaches and provide insight and indications of the functional appropriateness and usability.

The participants' ability to think-aloud and talking unfiltered affects these findings. However, it was anticipated that their ability to do this would vary. Therefore, the test emphasized on observations. The audio, video and eye tracking recording made it possible to be very thorough in the observation analysis process.

### **8.1.3 Credibility of visualization feasibility analysis**

The analysis that was performed on responses to the PAsTAs online questionnaire has some aspects that make it highly relevant for assessing feasibility of utilizing information visualization when providing health data to patients. However, the analysis was based on several assumptions and estimations, and the results must therefore be seen in this light.

#### **8.1.3.1 Real patient data**

The participants were presented their own patient data, retrieved from various health care organizations. Even though it was restricted to health service usage, this is a case of genuine utilization of information visualization techniques derived from state-of-the-art EHR visualization to present patient data to the patient themselves.

#### **8.1.3.2 Uncertainty in estimations and assumptions**

The feasibility was assessed by the answers to the question if the presentation of the health service usage was correct and the drop rate in the questionnaire when the visualization was introduced. This analysis is therefore based on data that did not provide full insight to what the patient was actually doing and their actual comprehension of the visualization. There is no way to say with complete certainty that a participant dropped out of the questionnaire due to the visualization, and if those who continued had understood and correctly interpreted the visualization.

In addition, the drop rate was based on estimates that could only assume on which step the participants dropped out of the questionnaire. However, the trend that most participants finished with the minimum number of steps required suggests that this assumption is correct.

## 8.2 Patients' perspective (RQ1)

This section discusses the findings concerning the patients' perspectives on online access to their health records, i.e. the findings in respect to research questions 1. This research question was broken down into four sub questions;

**RQ 1:** What are patients' perspectives on online access to their health records (i.e. a PHR that provides their EHRs) and how does these perspectives influence the way the health records should be presented?

**RQ1.1:**

Does patients consider it useful to gain online access to their health records?

**RQ1.2:** What use case support does patients consider important in a PHR that provides their EHRs?

**RQ1.3:** What information does the patients think is important to gain insight to about health services they have utilized?

**RQ1.4:**

Would patients consider sharing personally submitted data, and if so, with whom?

### 8.2.1 Perceived usefulness (RQ1.1)

The results from the questionnaire survey, together with the feedback from the test of functional appropriateness and usability, suggests that many patients perceives it very useful to gain insight to their health records. In the case study, several participants expressed a dissatisfaction with the overview their GP had of their health, and that it would be convenient to check things themselves rather than asking the GP.

Potentially, patients gaining access to their health records could also benefit the practitioners, as some patients would be more capable of discussing their health and reporting retrospective occurrences that might be relevant for the practitioner's analysis. However, the benefits for health care and society of patients gaining insight to their EHR data is much debated, but there are indications that further involvement of patients can improve healthcare, and that patients gaining access to EHR will support patient empowerment (Kopanitsa, Hildebrand, Stausberg, & Englmeier, 2013). In this debate, the patients' perspectives are often excluded. Even if there are no benefit in terms of better health for the patients in general, it could surely benefit patients with

great analytic abilities and health literacy. Thus, disregarding implementation costs, the question could be turned to ask if this could be harmful for some patients, cause less effective and efficient healthcare, and if it is morally justifiable to restrict patients' insight to the information health care providers have about them. More research is needed on the question of usefulness of PHRs that provides EHR data for society, but as the results in this report suggests, many patients thinks it would be beneficial for them personally. This complies with earlier indications that patients feel that the advantages outweigh the disadvantages (Kopanitsa, Hildebrand, Stausberg, & Englmeier, 2013).

### 8.2.2 Usage (RQ1.2)

From the survey results, it seems that patients would like the opportunity to have support for most of the suggested use cases; getting an overview of their health data, retrieving specific information such as test results and information about specific events, receiving information about their diagnoses and treatments, and give feedback to healthcare. These results does not necessarily represent how they would frequently use the system, but it suggests that these the use cases should be supported, and gives a sense of how functions should be prioritized in the user interface.

The frequency of usage of a function is not always representative for the perceived value of the function. When discussing an online health record, the frequency of usage of a function would be greatly affected by the individual user's health situation. For example, many patients might use the PHR often to check prescriptions, but would consider support of previewing indicator test values over time more important if they were to be diagnosed with cancer. Therefore, the implementation of use case support should not only consider frequency, but also the perceived importance of support. The importance of use cases should be reflected in the user interface to the degree it can. Participants in the survey were most concerned with health information retrieval on a general basis, i.e. test results, treatments and diagnoses. This indicates that presenting an overview of health information should be emphasized in the user interface.

The EPHVis prototype gave an overview of the events and periodic numeric values. It supports grouping events by different categories, e.g. by affiliation to disease or treatment, although, how events can be grouped would in a real case be dependent on the underlying health data. However, the prototype did not provide general information about diagnoses and treatments. Potentially, terms could be hyperlinked to external explanations, by providing these in the ontology. Nevertheless, how to present general information about treatments and diagnosis needs additional research.

Through the PAsTAs project, a qualitative workshop was conducted in Tromsø, Norway, where a group of cancer patients attended. The workshop was held to

investigate these patients' perspectives on online health records. These patients expressed that it was very important to provide functionality that enabled them to supply their own information. The participants wished to be able to add alternative treatments and diet, and use the application as a "health diary" (Wågbø, 2013). This is also the backbone of usual PHR solutions. However, the results in the survey suggest that most patients' primary concern is to gain insight to their EHR data.

### 8.2.3 Information (RQ1.3)

It seems that most patients wants more or less unrestricted insight to their EHRs. The perceived importance of information should be reflected in the health record presentation. If information visualization is utilized this should shape the accentuation of visual aids and the order of abstractions in the visualization. The results in the questionnaire survey indicates that diagnosis, treatment, measurement values and type of health service is of highest importance, but the numbers are not accurate enough to determine if this is representative for the general population.

As of writing, Helsenorge.no's service "My health" only provides time, service provider, service unit and specialist unit/specialty in the overview of health events<sup>37</sup>. In addition, it provides on-demand details for each event, where the address of the service provider is given. In the survey, where the event took place was rated lowest. In the estimated population mean, it only overlaps with the confidence interval of the names of clinicians responsible for the event. Nonetheless, the information is still perceived to be of some importance, but it should probably be projected with modesty in the user interface.

In the workshop in Tromsø 2013, several people in the group of cancer patients expressed that they did not value or did not wish to be confronted with test results in an online health record visualization. In fact, some expressed that this would cause them distress (Wågbø, 2013). The results of the survey contradicts these indications from the qualitative research in Tromsø. Although it might apply to their specific situations, this perspective does not seem to apply in general. The results of the questionnaire survey shows that, not only does patient which to view their test results, they consider it highly important. These findings complies with the research of Tulu et al., which found that looking at test results was the most utilized feature of the PHRs they examined (Tulu, et al., 2012).

However, as there are some patients that might experience distress from being confronted with certain data, it would be a good idea to make some mechanism available in the PHR that filters away this information. This is a difficult task

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<sup>37</sup> Translated from the table headings "period", "helseforetak", "tjenesteenhet" and "fagenhet/spesialitet" respectively.



since health data are so heterogeneous. Utilizing techniques similar to what was done in this project is an option, where detail data was conceptually constructed as a title and a value. Information could be filtered away by retrieving all titles, and giving the users the option of removing some of these from the health record presentation. Another possibility could be to provide the option of filtering away all numeric details.

As the importance of information varies between patients, it might also be a good idea to provide a flexible user interface that lets the user choose to a certain degree which information to emphasize. In the aspects of information visualization, this can be done by providing different visualizations suitable for emphasizing different information.

Nevertheless, the results of this project suggest that the starting point should be that all the suggested information is retrieved from the EHRs when it is possible. Additional research is needed to test these perspectives in a PHR solution that provides actual EHR data. The importance of information might be conceived differently dependent on the construct of the PHR's user interface and the information that is available in the EHRs.

#### **8.2.4 Patients supplying their own information (RQ1.4)**

The survey results suggest that patients are very open towards sharing their information with both clinicians and researchers. Most participants wanted to share everything with both clinicians and researchers or to choose with whom to share their supplemented information in each case. However, as there are some patients that do not wish to share their information, their desires must be respected. Thus, the PHR interfaces should provide options that lets the user choose whether to share all, none or to be asked each time they supplement their health records. In addition, the users should be able to choose with whom to share their information.

Although this in itself does not substantially influence the way the health records ought to be presented to patients, the result gives insight to the potential of using PHRs as a valuable resource for both patient-practitioner communication, and healthcare research and development.

## 8.3 Benefit of information visualization (RQ2)

This section discuss the results in respect to research question 2;

**RQ 2:** Would patients benefit from information visualization when presented with health records?

Results from the test of appropriateness and usability suggest that using a timeline for categorical data (events) and line charts for temporal numeric data is more functionally appropriate than a textual tabular representation. However, it seems to be few differences in usability, except in regards to efficiency, between the two prototypes in the context that they were used.

Of the major benefits, overview seems to be key. The participants that tested EPHVis seemed to benefit from a better overview of the patient data, compared to the participants that tested MHU. In this regard, the perspectives from the questionnaire survey should be considered, which indicate that overview should be emphasized in the interface.

In the HMU prototype, there were already comments on overflow of information on a health record of 19 events. A full-scale health record, spanning over many years, is probable to have more. This suggests that the lack of overview in a tabular format will become a severe issue as the health record becomes larger and more complex. Several participants that tested EPHVis commented the opposite, i.e. that it was a small health record. This may imply that patients will benefit from information visualization as the complexity of the health record grows.

The tabular format seems to be read systematically from the top or the bottom. As the number of events in the health record grows, this will probably become increasingly troublesome. The main issue seems to be that the tabular preview offers no way of abstracting time periods – this was also underpinned by the participant that wanted to divide events into years or months to make the overview more user friendly. The approach where the participants used the timeline seemed to be beneficial to them. They were more direct in their approach and used the time aspect and lane grouping to pinpoint the events they were looking for. This approach seemed to be a more efficient way of browsing health data, especially when the goal was to find specific events. Despite this approach being less thorough than the systematic reading that the participants that tested the MHU prototype, the participants that tested the EPHVis interface seemed to have a better overview and comprehension of the data they had tested, especially when it comes to implicit information. This suggests that the information visualization has provided them with information that is picked up by their subconscious. This is clearly a big benefit when browsing complex

temporal data sets as it may require less effort from the patients, but at the same time provide more information.

Other aspects might also be worth considering when assessing this question. For example, the EHR data in Norway are likely to be written in Norwegian. However, not all patients know how to read Norwegian, and those who are new to the language may struggle. Utilization of visual aids might facilitate to overcome this language barrier. An alternate aspect here would be to use the visualization as a tool of communicating between practitioner and patient (Weibel, et al., 2013).

From the EHR visualization intended for practitioners, some research suggests that it is beneficial for them (Zhu, Gold, Lai, Hripcsak, & Cimino, 2009). From this project it also seems that it is a good idea to derive techniques from these visualizations to present health records to patients. However, it must be considered that the intended usage of the visualization is different. The EHR visualization techniques that have been developed for practitioners are often concerned with medical analysis. Visualizations that are intended for patients, needs to consider their perspectives and needs.

## 8.4 Feasibility of information visualization to patients (RQ3)

This section discuss the findings in respect to the feasibility of utilizing information visualization when presenting health records to patients. Hence, the discussion is in consideration of research question 3;

### **RQ 3:**

Is it feasible to utilize information visualization techniques derived from state-of-the-art EHR visualization to present health data to patients?

The visualization that was included into the PAsTAs questionnaire were limited to an overview of the health services that the patient had used during a two-year period (2011 and 2012). Limited amount of details were given to the participants because of limitations in the underlying data, and for privacy and security reasons. Therefore, the visualization was simplified in the sense that it did not provide functionally beyond the timeline visualization where events were represented as dots and rectangles and on-demand detail were limited to the length of the event in terms of days. Hence, the visualization did not provide information, interactivity and functions to the extent that a full EHR visualization would. Nevertheless, the concepts of showing health events in a timeline and giving on-demand details in tooltips are the same, and the results imply that this concept is feasible for patients.

Patients with inefficient computer literacy are often highlighted as one of the main concerns of utilizing information visualization in PHRs. Although this might be true, it seems to be assumed that textual solutions are easier to use than information visualization. If we consider how health records can be very complex, it is not certain that information visualization is more difficult than a textual presentation. Information visualization exploits human cognition, and this may simplify browsing complex data and facilitate ease of use (Weibel, et al., 2013). Although none of the participants in the test of functional appropriateness and usability suffered from computer illiteracy, it seemed that the participants found it easier to use the interactive information visualization prototype EPHVis than the text based tabular prototype HMU.

Additionally, the visualization in PAsTAs Web was introduced into the questionnaire without an explanation of the visual components or how to interact with the visualization. There was however, a small optional help text available that could be accessed by clicking a help icon above the visualization<sup>38</sup>. Thus, there was no, or very little, instructions given to the patients before they were presented with the visualization. Despite this, it seems that the visualization did not cause problems for the participants.

The qualitative case studies that were performed on the PAsTAs Web application in the fall of 2013, and the testing done on EPHVis during this project indicates the same (Wågbo, 2013). During these tests, none of the participants had problems understanding or interpreting the timeline visualization. These case studies also suggests that patients understand the interaction with the timeline and that events on the timeline are intuitively inspect by clicking or hovering them. However, more research is needed to assess how patients in general cope with more advanced functions in the visualization, such as zooming, panning, filtering, and changing event grouping.

As an endnote to the discussion of this research question, the perspective that was used in the visualization was temporal events grouped by their corresponding service provider. As this seems to be feasible for patients, it might also be a good starting point for other timeline visualizations.

## 8.5 Limitations

The discussion above has given some insight to the limitations of the research methods and their execution. This chapter continue the discussion of these limitations.

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<sup>38</sup> The help text contained only 25 words and described what was shown and how to interact with the timeline.

## **8.5.1 Limitations of the online questionnaire**

This section discusses limitations of the online questionnaire survey. The credibility section above gives some additional insight to the limitations of the survey.

### **8.5.1.1 Limited sample**

There were no questions about nationality or residence. However, seeing how distribution of flyers took place in Trondheim, Norway, and the questionnaire was in Norwegian, it is highly likely that the participants were Norwegian-speaking people living in Trondheim, Norway.

### **8.5.1.2 Sampling**

The sampling process could have been done in a better way. Although it is likely that the sample that received invitations were random, it is not certain. Generating a random sample from official residential information could have been a better solution.

The voluntary bias was probably diminished by the optional contest, however might not have eliminated it. It is hard to avoid bias in a questionnaire, but a larger sample size would have helped.

### **8.5.1.3 Survey context / introduction**

As with many questionnaire surveys, the introduction to the survey could have been more extensive. It was kept quite short to prevent drop of participation due to additional effort. Although there were no reports of participants having problems understanding the context, optimally, they might have been more suited for answering the questions if they had a deeper understanding for the research.

### **8.5.1.4 Questionnaire questions**

As this project assess information visualization of health records to patients, this questionnaire could have included examples of different presentations and asked participants about them. However, this was found to be too difficult, especially since the content would have to be fictive without a permit from REK, but also because of the time limitation.

The questions in the questionnaire is also a limitation in mapping the perspectives of patients. There may be aspects that was not considered in the questionnaire, that are important in mapping the patients perspectives. This was also the reason textual input fields were provided in the questionnaire. This allowed some flexibility in the perspectives the participants could convey.

## 8.5.2 Limitations of test of functional appropriateness and usability

This section discusses some limitations of the test of functional appropriateness and usability.

### 8.5.2.1 Prototypes

The prototypes were just that, prototypes. They were developed during this project to assess the concept, and therefore do not contain everything that a full-scale implementation of a PHR should contain. They are restricted to browsing time dependent health events that can contain some additional textual, pictorial, numerical and categorical details. A full-scale PHR should consider extending these functionalities to provide prescriptions, personal data, vaccination and more. It should also be considered to have several different ways of visualizing numerical data that are not necessarily bound by time representation as in the EPHVis prototype. Nevertheless, as the test gave the participants specific user tasks, this was not a problem for the test.

Some of the functions that were implemented could have been solved more elegantly. One “bug” that confused some of the participants that tested the HMU prototype was that a search query returned a list of events sorted by hit rate on the query, but they were not notified about this change. Some participants noticed the error after systematically going through events and some did not notice this error at all. Although an outcome from an unintentional bug, this supports the claim that a timeline representation is more functional appropriate than a tabular representation.

The HMU prototype could also have provided different columns in the overview table. To make it realistic as possible the columns from [helsenorge.no](http://helsenorge.no) was used.

In the EPHVis prototype it also became apparent that it should have handled smaller screens better. The left side menu became a bit too dominating when the resolution was diminished during the test. This happened because the test software, Tobii studio, reduced the resolution of the website, making it bigger on-screen. Some participants also commented that they would like to see some more context around the timeline. Fitting it in to a simulated shell, as it was done with the MHU prototype that used the surrounding layout of [helsenorge.no](http://helsenorge.no), might have made the prototype feel more realistic. However, it is doubtful that this had substantial implications on the test.

### 8.5.2.2 Patient case with fictive data

The patient case was a compromise to make the test as realistic as possible, without real patient data. It would obviously have been better if the test was on patients and their real health records. This was not possible due to legislations

and technical impractical as EHRs are scattered across several health organizations in different formats.

The fictive health record that was provided in the test was also limited. It contained 19 events over a period of 4 years. It was kept small to make the execution of the test feasible. In a real health record, this might be substantially higher, especially if the patient has experienced health issues. It is uncertain what the outfall would have been of substantially lower or higher data volume.

### **8.5.2.3 User tasks**

The user tasks were specific tasks that were meant to be somewhat covering for typical use cases related to patients browsing their health record. They had to be limited due to the time restriction and to make the test feasible for the participants. More extensive user tasks may have contributed to additional observations.

### **8.5.2.4 Participants**

The participants were recruited from friends, family and acquaintances. Although it was stated during the test sessions that they should be critical towards the prototypes, this may have influenced the way their formulations. They were not informed about where the prototype originated from, so there would be no bias towards one prototype. They were told that they were to test “some prototype”.

It is also noteworthy that none of the participants saw their computer skill level as “novice”. Most participants saw their computer skill level as “medium” or “advanced”. One participant had a “expert” self-perceived computer skill level.

### **8.5.2.5 Observation**

Although audio, video, screen and eye tracking was recorded, and these recordings were used in the analysis, the observations were still analyzed by one person. It is not certain that this is a limitation, but it is possible that additional people in the analysis process would have uncovered further observations.

### **8.5.2.6 SUS standard**

The SUS questions are standard, and all on them were not relevant for assessing the prototypes, especially not the question that asked the participants how often they would use the system. This is dependent on the patient’s health situation, and does not necessarily translate to satisfaction. Therefore, the SUS scores should only be considered as a supplement to the other findings, and not emphasized on their own.

### **8.5.2.7 Variables**

This test assessed functional appropriateness and usability. There might be other benefits or drawbacks in the different ways of presenting health records to patients that this test does not cover.

## **8.5.3 Limitations in the visualization feasibility analysis**

This section discusses the most important limitations of the feasibility analysis of that was done on the PAsTAs survey submissions to the online questionnaire.

### **8.5.3.1 Uncertainty in estimations**

It would have been beneficial for the drop rate analysis if information about which step a submission originated from had been saved during the data collection process. However, the need for this information was identified after the online questionnaire had been launched, at a time when it was too late to implement.

### **8.5.3.2 Limited health data**

As mentioned the visualization that was provided in the PAsTAs Web application only previewed health service usage over a two year period. It would have been beneficial for this project if the visualization provided full EHRs.

### **8.5.3.3 Limited sample**

The sample that the PAsTAs project survey are patients that have at least one chronic diagnosis. These patients may represent a group of patients that have elevated health literacy. This could have given the participants an edge in understanding the visualization, especially that health services were grouped by service provider. However, this is not certain.

In addition, it is probable that those who choose to access the online questionnaire, instead of getting the paper version, have a certain level of computer literacy. However, this is limitation that generally applies to any website.

### **8.5.3.4 Limited insight**

The results from the analysis of the PAsTAs survey responses do not say anything about how the participants browsed the data in the visualization that were provided to them. Therefore, it remains unanswered if they interacted with the timeline, or just gazed at it, and if they did interact with it, how this interacted was performed.



# 9 Conclusion

In this project, an online questionnaire was conducted on 103 people to investigate patients' attitude and perspectives towards gaining online access to their health records. Potential benefits or drawbacks of utilizing information visualization when presenting health data to patients was assessed through a case study which investigated functional appropriateness and usability of two prototypes, one that utilized visualization techniques derived from state-of-the-art EHR visualization, and one that presents health data on a textual tabular format. The feasibility of utilizing information visualization to present health data to patients was investigated by analyzing the responses to the PAsTAs online questionnaire.

The results seems to suggest that patients desire full insight to their EHRs, and are very open-minded towards sharing information they themselves were to supplement to a PHR system with researchers and clinicians.

It seems that much of the EHR visualization techniques intended for practitioners is transferable to visualizing health data to patients. Timeline visualization seems to be feasible. However, the visualization needs to be adapted to the patients' perspectives. Visualization techniques intended for on-the-fly medical analysis is probable to not suite the patients' perspectives; the patients seem to be interested in gaining information and reminiscence about their health. Nonetheless, it seems that patients are interested in gaining insight to the actual health data from their medical examinations, such as measurement test results and medical images.

The case study results suggests that visualizing health records as events on an interactive timeline, and providing line charts for temporal measurements, provides an overview of the health data that is not gained when presented on a text-based tabular format. Additionally the interactive timeline seems to provide a less troublesome way of browsing health data. Thus, it seems to be better suited, i.e. more functional appropriate, for presenting health data to patients. Nevertheless, both ways of presenting health data seems to be usable.

Much research is still needed on how to present health records to patients. Some future works that should be considered is suggested in the next chapter.

# 10 Future works

This chapter gives some recommendations for future works and research in the aspect of utilizing information visualization to present health records to patients.

## 10.1 Health illiteracy support

As Faisal et al. points out the patients need more support interpreting data than practitioners (Faisal, Blandford, & Potts, Making sense of personal health information: Challenges for information visualization, 2012).

With today's technology and widespread use of the Web, information is just a keystroke away. Thus, health illiteracy may not be as big an issue as it was 10 years ago. Nevertheless, it is highly important that the patients are given correct information and that a suitable authority has assessed this information. Sources such as Wikipedia.org are not suitable to provide such information. It is also very important that the information that is provided is adequate for the patients' information need. It is undesirable that they search the web themselves for answers, as they may find information that is incorrect.

The work with medical term "lookup" mechanism was started in this project, but not finished. The idea was to make medical terms hyperlinked in the user interfaces, which sends the user to external sources that provides explanation. There are many different aspects to consider in this context. Firstly, it is highly important that the solution is accurate; the lookup must preserve the semantic in the medical term. The consequences of providing the wrong information could cause confusion, misunderstandings and even distrust between patient and practitioner. Because of this, one should be careful with using a search-based solution.

A search for external sources, restricted to Norwegian, identified three Web services that provides quality controlled content about clinical terms and may be suitable for medical term information:

- Legemiddelhåndboka<sup>39</sup>
- Norsk helseinformatikk<sup>40</sup>
- Store Medisinske Leksikon<sup>41</sup>

Legemiddelhåndboka translates to «Remedy handbook», is a web service that provides independent description of remedies, treatments and general

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<sup>39</sup> [www.legemiddelhandboka.no](http://www.legemiddelhandboka.no)

<sup>40</sup> [www.nhi.no](http://www.nhi.no)

<sup>41</sup> [sml.snl.no](http://sml.snl.no)

information about illnesses. It provides information at several levels of abstractions, e.g. generally about allergic illnesses and more specific about vernal conjunctivitis. All the information is textual that is primarily made for practitioners. A general search engine is provided that query the articles on the site.

Norsk Helseinformatikk, translates to «Norwegian health informatics», is a web service provides health information to patients. The service includes general health articles, information about specific illnesses, symptom checklists, and lifestyle and training articles. The information is mostly textual and short with few illustrations. A general search engine is provided that query the articles on the site.

“Store Medisinske Leksikon”, translates to «Big Medical Encyclopedia», is as described by its title an encyclopedia of medical terms. It has over 13000 articles on illnesses, medical terms, symptoms, treatments and more. The web service provides a general search engine like the others that query the articles available.

Nevertheless, further research is needed to investigate how this could be solved, and what kind of lookup that is appropriate.

## 10.2 Coupling with EHR

Research is required in studying the way patients perceive EHR data (Kopanitsa, Hildebrand, Stausberg, & Englmeier, 2013). In this project the health data that were presented to patients were either restricted their usage of health services or fictive. The next step in researching the patients' perspectives on health record visualization would be to couple the visualization to an actual EHR that can provide real and extensive health data.

## 10.3 Icon event categorization

Some EHR visualizations utilize icons to represent events on the timeline. Although the EPHS system supports such integration, further research is needed to map if icons are appropriate in health record visualization to patients. If they are appropriate, research must also answer which icons should be used and who should control the use and layout of these icons; users, administrators or others.

## 10.4 Color categorization

Color categorization is one of the things that is often used in EHR visualizations to differ types of events. Although a slight color difference between point and

interval events were used in the PAsTAs survey, further research is needed on the usage and utility of color categorization in health record visualization to patients. Considerations such as color blindness need to be assessed in this research.

## **10.5 Handling time uncertainty**

The timeline visualization that was developed as part of this project is dependent on placing events according to time. In health, data there can exist uncertainty when a certain event took place, when it started, when it ended or both. Additional work is needed to assess solutions for handling such uncertainties. Zhu et al. have looked into the issue in the context of EHR visualization, and suggested solutions (Zhu, Gold, Lai, Hripcsak, & Cimino, 2009).

## **10.6 Handling general patient information**

There are several research papers describing PHR requirements and handling of general information, however how this could be integrated into a health record visualization has not been assessed. Such information handling will be necessary in a complete PHR implementation.

## **10.7 Health data analysis support**

Patients may need support to understand and analyze the health data they are presented with. Some of the EHR visualizations intended for practitioners aggregate test result values over categorical indicators such as “low, normal, high” (Rind, et al., 2011). Research is needed to investigate which sort of support should be integrated, and how it should be integrated into health record visualization to patients.

## **10.8 Computer illiteracy**

It is unclear where the lower bound limit lies for computer literacy in order to be able to use information visualization. The results in this project indicates that the visualization is feasible for most patients, but if utilizing information visualization requires that users have more sophisticated computer skills than needed in order to use other textual solutions remains an unanswered question.

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# Appendix A : EPHS main ontology in Manchester syntax (OWL)

This appendix gives the EPHS main ontology in Manchester syntax. An overview of the Manchester syntax can be gained in W3C's recommendation titled *OWL 2 Web Ontology Language Manchester Syntax* (W3C, 2012).



Prefix: owl: <http://www.w3.org/2002/07/owl#>  
Prefix: rdf: <http://www.w3.org/1999/02/22-rdf-syntax-ns#>  
Prefix: xml: <http://www.w3.org/XML/1998/namespace>  
Prefix: xsd: <http://www.w3.org/2001/XMLSchema#>  
Prefix: rdfs: <http://www.w3.org/2000/01/rdf-schema#>  
Prefix: epicurus: <http://www.epicurus.no/ontology#>

Ontology: <http://www.epicurus.no/ontology#>

Datatype: rdf:PlainLiteral  
Datatype: xsd:positiveInteger  
Datatype: xsd:language  
Datatype: xsd:anyURI  
Datatype: xsd:boolean  
Datatype: xsd:string  
Datatype: xsd:dateTime  
Datatype: xsd:integer

ObjectProperty: epicurus:hasVisualDetail  
SubPropertyOf:  
    owl:topObjectProperty  
Domain:  
    epicurus:VisualEntry  
Range:  
    epicurus:VisualDetail

ObjectProperty: owl:topObjectProperty

DataProperty: epicurus:hasValue  
SubPropertyOf:  
    owl:topDataProperty

DataProperty: epicurus:hasStartTime  
Range:  
    xsd:dateTime  
SubPropertyOf:  
    owl:topDataProperty

DataProperty: epicurus:hasIcon  
Domain:  
    epicurus:VisualElement  
Range:  
    xsd:anyURI  
  
SubPropertyOf:  
    owl:topDataProperty

DataProperty: epicurus:hasEndTime

Range:

xsd:dateTime

SubPropertyOf:

owl:topDataProperty

DataProperty: epicurus:hasTitle

Range:

xsd:string

SubPropertyOf:

owl:topDataProperty

DataProperty: epicurus:isVisible

Domain:

epicurus:VisualElement

Range:

xsd:boolean

DataProperty: owl:topDataProperty

Class: owl:Thing

Class: epicurus:QuantifiableDetail

SubClassOf:

epicurus:VisualDetail

Class: epicurus:VisualInterval

SubClassOf:

epicurus:hasEndTime exactly 1 xsd:dateTime,  
epicurus:VisualEntry

DisjointWith:

epicurus:VisualPoint

Class: epicurus:CategoricalDetail

SubClassOf:

epicurus:VisualDetail

Class: epicurus:VisualDetail

SubClassOf:

epicurus:hasTitle exactly 1 xsd:string,  
epicurus:hasValue exactly 1 rdf:PlainLiteral,  
epicurus:VisualElement

Class: epicurus:VisualPoint

SubClassOf:

epicurus:hasEndTime max 1 xsd:dateTime,  
epicurus:VisualEntry

DisjointWith:

epicurus:VisualInterval

Class: epicurus:VisualEntry

SubClassOf:

epicurus:VisualElement,

epicurus:hasStartTime exactly 1 xsd:dateTime

Class: epicurus:VisualElement

SubClassOf:

owl:Thing

Class: epicurus:PictorialDetail

SubClassOf:

epicurus:VisualDetail

# **Appendix B :**

# **Questions from**

# **questionnaire survey**

This appendix lists the questions included in the survey, translated from Norwegian.

## B.1 General personal background

- 1) How old are you? (enter number of years)
- 2) Sex:
  - a) Male
  - b) Female
- 3) Which education is the highest you have completed?
  - a) Primary school (7-10 years)
  - b) Secondary school
  - c) Collage / university, less than 4 years
  - d) Collage / university, more than 4 years
- 4) Which of the following is most representative for your main activity?
  - a) Employee or self-employed
  - b) Retired
  - c) On welfare
  - d) Homemaker
  - e) Student
  - f) Jobseeker

## B.2 Personal health and health care affiliation

- 5) Are you educated in, or do you work with health?
  - a) Yes
  - b) No
- 6) Approximately, how often do you use health care services?
  - a) Rarer than once a year
  - b) 1-3 times a year
  - c) 3-12 times a year
  - d) 1-2 times a month
  - e) 2-4 times a month
  - f) more than 4 time a month
- 7) Have you received any chronic diagnoses?
  - a) No
  - b) Yes, 1 time
  - c) Yes, 2-3 times
  - d) Yes, 4 or more times
- 8) On a scale of 1-6, how do they rate their own health?  
1 = as bad as it can be,  
6 = as good as it can be

## B.3 Computer skills

- 9) How do you consider your computer skills?
- a) Novice
  - b) Intermediate
  - c) Advanced
  - d) Expert
- 10) How often do you use the Internet?
- a) Never to once a week
  - b) 1 to 3 times a week
  - c) 3 to 5 times a week
  - d) Every day
- 11) How many different websites do you visit in a week?
- a) 0 to 1
  - b) 2 to 5
  - c) 5 to 10
  - d) 10+

## B.4 Application usage

- 12) Would it be useful for you to gain access to your own health record online?
- a) Yes
  - b) No
  - c) Don't know
- 13) If you gained access to your health record online, how important would it be for you to be able to use the website for the following purposes?  
Rank on a scale from 1 to 6!  
1 = not important at all  
6 = very important
- a) Find information about my diagnoses / conditions / illnesses
  - b) Find information about my treatments and/or medications
  - c) View health history / help remembering what has happened
  - d) Keep myself informed about which data the health service have about me
  - e) Add my own information / write comments
  - f) Plan / look up future appointments and events
  - g) Look at test results
  - h) Search for / preview information about specific events or health services
  - i) Give feedback to the health service about my experiences / my perspective

- 14) Are there other things you wish to use the website for? (enter free text)  
(optional)

## B.5 Perspective of health care services

- 15) If you gained access to your health record online, how important would you consider it to be presented with the following information about health services you have used?

Examples of health services are: Consultation with your GP; admission to hospital; radiology at a private clinic; operation at a hospital.

Rank on a scale from 1 to 6 how important you consider the information!

1 = not important at all

2 = very important

- a) Time / date / period  
(e.g. from January 1<sup>st</sup> to February 3<sup>rd</sup>, 2012)
  - b) Event place / address / building  
(e.g. Prinsesse Kristians gate 3)
  - c) Service provider  
(e.g. St. Olavs Hospital, Rosten medical center, Trondheim kommune)
  - d) Type of service provider  
(e.g. hospital, GP, private clinic)
  - e) Type of health service  
(e.g. x-ray, GP visit, blood test)
  - f) Name of clinician(s) that provided or were responsible for the service  
(e.g. dr. Ola Normann)
  - g) Diagnosis / symptom(s) / illness(es)  
(e.g. diabetes melitus, leg fracture)
  - h) Procedure / the thing that was performed  
(e.g. check of reflexes, measurement of blood pressure)
  - i) Treatment / medication  
(e.g. Paracet Forte 3 times/day)
  - j) Values of measurements  
(e.g. blood pressure 120/80 mmHg)
  - k) Medical imaging / pictures taken  
(e.g. pictures from x-ray examination)
  - l) Prognosis / expected outcomes of disease state  
(e.g. 30% chance of cardiovascular disease)
- 16) Are there other information you would like to have presented about your health services? (enter free text)(optional)

## B.6 Supplementing and sharing of data

- 17) If you added your own health information to your health record, would you share this information with researchers and/or clinicians?
- a) Yes, with both researchers and clinicians
  - b) Yes, but only with researchers
  - c) Yes, but only with clinicians
  - d) Yes, but only with my GP
  - e) I would like to choose each time
  - f) None, no one
  - g) Don't know

## B.7 Comments and competition

- 18) Below you can enter comments that you may want to give to the survey!  
(enter free text)(optional)



# **Appendix C : Screens of the questionnaire survey**

This appendix gives screens from the questionnaire.

**P-journal.no**

## Personlig journal

[Prosjekt om presentasjon av pasientjournal på nett](#)

Sporreundersøkelsen har som hensikt å kartlegge pasienters behov ved presentasjon av egen pasientjournal på nett.

Ved slutten av undersøkelsen kan du delta i en konkurranse om å vinne et splitter nytt [nettbrett!](#)

Undersøkelsen vil ta rundt 5 minutter!

**Trykk på knappen under for å delta!**

**START UNDERSØKELSEN!** 



**NTNU**

Det skapende universitet

Spørsmål: [support@p-journal.no](mailto:support@p-journal.no)

**P-journal.no**

1 **Hvor gammel er du?**  
33 år

2 **Kjønn:**  
 Mann  
 Kvinne

3 **Hvilken utdanning er den høyeste du har fullført?**  
 Grunnskole (7-10 år)  
 Videregående skole  
 Høgskole / Universitet, mindre enn 4 år  
 Høgskole / Universitet, mer enn 4 år

4 **Hvilken av de følgende er mest dekkende for din hovedaktivitet?**  
 Ansatt eller selvstendig næringsdrivende  
 Pensjonist  
 Trygdet  
 Hjemmeværende  
 Student  
 Arbeidssøker

5 **Er du utdannet i, eller jobber du med helse?**  
 Ja  
 Nei

6 **Omtrent hvor ofte bruker du helsetjenester?**  
 Sjeldnere enn 1 gang i året  
 1-3 ganger i året  
 3-12 ganger i året  
 1-2 ganger i måneden  
 2-4 ganger i måneden  
 mer enn 4 ganger i måneden

7 **Har du mottatt kroniske diagnoser?**  
 Nei  
 Ja, 1 gang  
 Ja, 2-3 ganger  
 Ja, 4 eller flere ganger

8 **På en skala fra 1 til 6, hvordan vil du vurdere din egen helse?**  
1 = så ille som det kan bli  
6 = så bra som det kan bli  
 1  2  3  4  5  6

9 **Hvordan vil du vurdere dine dataferdigheter?**  
 Nybegynner  
 Middels  
 Avansert  
 Ekspert

10 **Hvor ofte bruker du Internett?**  
 Aldri til en gang i uken  
 1 til 3 ganger i uken  
 3 til 5 ganger i uken  
 Hver dag

11 **Hvor mange forskjellige nettsteder besøker du i løpet av en uke?**  
 0 til 1  
 2 til 5  
 5 til 10  
 10+

## P-journal.no

20 Ville det vært nyttig for deg å ha tilgang til din pasientjournal på nett?

- Ja  
 Nei  
 Vet ikke

21 Hvis du fikk tilgang til din pasientjournal på nett, hvor viktig er det for deg å kunne bruke nettstedet til følgende formål?

Ranger på en skala fra 1 til 6!

1 = ikke viktig i det hele tatt  
6 = veldig viktig

	1	2	3	4	5	6
Finne informasjon om mine diagnoser / tilstander / sykdommer	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finne informasjon om mine behandlinger og/eller medisiner	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Se helsehistorikk / Hjelp til å huske hva som har skjedd	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Holde meg informert om hvilke data helsevesenet har om meg	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Legge til egen informasjon / skrive kommentarer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Planlegge / slå opp fremtidige avtaler og hendelser	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Se på testresultater	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Søke etter / se på informasjon om spesifikke hendelser eller helsetjenester	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gi tilbakemelding til helsevesenet om mine opplevelser / mitt perspektiv	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

22 Er det andre ting du ønsker å kunne bruke nettstedet til?  
(300 tegn igjen).

**23 Hvis du fikk tilgang til din pasientjournal på nett, hvor viktig syns du det er å få presentert følgende informasjon om helsetjenester du har benyttet deg av?**

Eksempler på helsetjenester er: *Konsultasjon hos fastlegen, innleggelse på sykehus, røntgenundersøkelse hos privatklinikk, operasjon på sykehus.*

**Ranger på en skala fra 1 til 6 hvor viktig du syns informasjonen er!**

1 = ikke viktig i det hele tatt

6 = veldig viktig

	1	2	3	4	5	6
<b>Tidspunkt / dato / periode</b> (f.eks fra 1. januar til 3. februar, 2012)	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Hendelsessted / adresse / bygning</b> (f.eks Prinsesse Kristinas gate 3, Trondheim)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Tjenesteyter</b> (f.eks St. Olavs Hospital, Rosten legesenter, Trondheim Kommune)	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Type tjenesteyter</b> (f.eks sykehus, fastlege, privatklinikk)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
<b>Type helsetjeneste</b> (f.eks røntgen, fastlegebesøk, blodprøve)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Navn på kliniker(e) som utførte eller var ansvarlig for tjenesten</b> (f.eks dr. Ola Normann)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
<b>Diagnose / symptom(er) / sykdom(er)</b> (f.eks diabetes melitus, leggbrudd)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Prosedyre / det som ble utført</b> (f.eks sjekk av reflekser, måling av blodtrykk)	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Behandling / medisiner</b> (f.eks Paracet Forte 3 ganger/døgn)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
<b>Verdier på målinger</b> (f.eks blodtrykk 120/80 mmHg)	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Billediagnostikk / Bilder som ble tatt</b> (f.eks bilder fra røntgenundersøkelse)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Prognose / antatt utfall av sykdomstilstand</b> (f.eks 30% sjanse for hjerte- og karsykdom)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**24 Er det annen informasjon du ønsker å få opp om dine helsetjenester?**  
(300 tegn igjen).

**25 Hvis du selv la til informasjon i din pasientjournal, vil du dele denne informasjonen med forskere og/eller helsepersonell?**

- Ja, med både forskere og helsepersonell
- Ja, men bare med forskere
- Ja, men bare med helsepersonell
- Ja, men bare med fastlegen min
- Jeg ønsker å kunne bestemme i hvert enkelt tilfelle
- Nei, ingen
- Vet ikke

**26 Nedenfor kan du skrive inn kommentarer som du eventuelt ønsker å gi om undersøkelsen!**  
(300 tegn igjen).

**27 Dersom du ønsker å delta i trekningen av nettbrett kan du skrive inn telefonnummeret ditt her!**  
(dette knyttes ikke til svarene du har avigtt).

# **Appendix D :**

# **Test of functional appropriateness and usability**

This appendix gives the test of functional appropriateness as given to the participants (except for the retrospective interview, which was done purely orally).

## D.1 Samtykke- og taushetserklæring

Jeg deltar frivillig i brukervennlighetstesting i forbindelse med Håkon Dale Wågbo sin mastergradsoppgave.

Som testbruker har jeg rett til å avbryte testen når som helst uten begrunnelse.

Jeg er anonym, og mine personalia og kontaktinformasjon skal ikke offentliggjøres eller brukes i en annen sammenheng. Dersom jeg ønsker det, har jeg rett til å få slettet ev. opptak. Som kompensasjon for deltakelse mottar jeg

---

### **Samtykke til opptak**

Det vil bli gjort opptak av lyd, bilde og skjerminteraksjon. Jeg samtykker til at disse opptakene kan brukes til systemanalyse, og jeg fraskriver meg herved all rettigheter til opptaket.

### **Taushetserklæring**

Den informasjon og kunnskap om systemet som jeg tilegner meg, erklærer jeg herved at jeg ikke skal dele med andre.

---

**Navn**

**Sted/Dato**

---

**Signatur**

## D.2 Innledende spørsmål

1. Navn
2. Alder
3. Hva er din foreløpige utdanning og/eller yrke
4. Har du noen gang hatt jobb, eller har du utdanning, relatert til helse? I så fall hva?
5. Hvordan vil du gradere dataferdighetene dine? (sett ring)
  - a. Nybegynner
  - b. Middels
  - c. Avansert
  - d. Ekspert
6. Omtrentlig hvor ofte bruker du Internett? (sett ring)
  - a. 0 til 3 ganger i uken
  - b. 3 til 5 ganger i uken
  - c. Én gang om dag
  - d. 2-3 ganger om dagen
  - e. 4-5 ganger om dagen
  - f. Over 5 ganger om dagen
7. Omtrentlig hvor mange forskjellige nettstedet besøker du i løpet av en dag? (sett ring)
  - a. 0 til 1
  - b. 2 til 5
  - c. 6 til 10
  - d. 10+



## D.3 Bakgrunnshistorie

Per Pasient er en 70 år gammel mann fra Trondheim. Han ble diagnostisert med diabetes type 1 når han var 50 år. Han har levd med denne sykdommen uten komplikasjoner de siste 20 årene.

For nesten 4 år siden fikk Per diagnosen prostatakreft. Han ble raskt innlagt på sykehus og svulsten ble operert bort. Selv om operasjonen var en suksess, har Per regelmessig vært til legen for å passe på at kreften ikke kommer tilbake.

Siden Per er i ferd med å bli eldre og har problemer med å huske ting, har han spurt deg om å være hans støttekontakt, for å hjelpe han på veien til bedre helse. I den sammenheng har du fått tilgang til Pers personlige pasient journal, som er tilgjengelig på nettet. Per og du har sammen identifisert noen oppgaver som du må gjøre for å oppnå bedre forståelse for Pers helse de siste årene.

## D.4Oppgaver

- 6) Mål: Finne Pers innleggelse på St. Olavs i 2012, finn ut hvilken informasjon som fins om innleggelsen.
  - a. Finn hendelsen i forløpet (Innleggelse på St. Olavs 2012)
  - b. Trykk på hendelsen og se hva som står der
  
- 7) Mål: Finne sist tidspunkt Per var hos fastlegen og finne ut hva PSA ble målt til da.
  - a. Finn den siste hendelsen på Rosten legesenter
  - b. Trykk på hendelsen og se hva som står der
  
- 8) Mål: Finne ut når Per sist var på rutinesjekk i forhold til diabetes. Disse finner sted noen ganger hos St. Olavs og noen ganger hos fastlegen
  - a. Finn den siste hendelsen knyttet til diabetes
  - b. Se når hendelsen tok sted
  
- 9) Mål: Skaff deg oversikt over hba1c- og PSA-prøver som er tatt.
  - a. (EPHVis) lag diagram over hba1c- og PSA-prøver
  - b. (helsenorge) finn hendelser med hba1c- eller PSA-prøver og inspiser
  
- 10) Mål: Finne siste gang Per var til MR-undersøkelse og finn ut hvilken diagnose som ble gitt på denne undersøkelsen.
  - a. Finn hendelsen
  - b. Trykk på hendelsen og se på diagnosen som ble stilt

## D.5 Retrospektivt intervju

### Nøyaktighet og oversikt av forløpserindring

Hvis du tenker tilbake på det som hadde skjedd med Per:

1. Omtrentlig hvor mange tjenesteytere (som f.eks St.Olavs) hadde Per vært innom (hvor mange «plasser» hadde Per vært)?
2. Husker du navet på noen av disse tjenesteyterne (hvor hadde Per vært)?
3. Husker du om Per hadde vært på St. Olavs i år (2014)?
4. I oppgave 1 skulle du finne en innleggelse i 2012 på St. Olavs, hadde Per vært innlagt på St. Olavs noen gang etter dette?
5. (Hvis ja i 4) Når omtrentlig var dette?
6. I oppgave 5 skulle du finne en MR-undersøkelse. Denne undersøkelsen fant sted hos Unilabs. Husker du om Per hadde vært hos Unilabs flere ganger utenom denne undersøkelsen?
7. Når omtrentlig var MR-undersøkelsen?
8. Omtrentlig hvor ofte var Per til fastlegen (Rosten legesenter)?
9. I oppgave skulle du skaffe deg oversikt over hba1c og PSA målinger, så du noen sammenheng mellom disse?

### **Forståelse og tilbakemeldinger**

1. Hva syns du om systemet?
2. Hva syns du var vanskelig?
3. Hva syns du var lett?
4. Hvordan ville du oppleve å få dine egne helsedata presentert på denne måten?
5. Har du andre forbedringsforslag eller tilbakemeldinger?

## D.6SUS spørreskjema

Vennligst sett kryss i kun en rute pr. spørsmål.

- |   | Sterkt<br>u<br>e<br>n<br>i<br>g |                          |                          |                          | Sterkt<br>e<br>n<br>i<br>g |
|---|---------------------------------|--------------------------|--------------------------|--------------------------|----------------------------|
| 1. Jeg kunne tenke meg å bruke dette systemet ofte.   | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>   |
|   | 1                               | 2                        | 3                        | 4                        | 5                          |
| 2. Jeg synes systemet var unødvendig komplisert.  | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>   |
|   | 1                               | 2                        | 3                        | 4                        | 5                          |
| 3. Jeg synes systemet var lett å bruke.   | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>   |
|   | 1                               | 2                        | 3                        | 4                        | 5                          |
| 4. Jeg tror jeg vil måtte trenge hjelp fra en person med teknisk kunnskap for å kunne bruke dette systemet. | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>   |
|   | 1                               | 2                        | 3                        | 4                        | 5                          |
| 5. Jeg syntes at de forskjellige delene av systemet hang godt sammen.                                       | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>   |
|   | 1                               | 2                        | 3                        | 4                        | 5                          |
| 6. Jeg syntes det var for mye inkonsistens i systemet (Det virket «ulogisk»).                               | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>   |
|   | 1                               | 2                        | 3                        | 4                        | 5                          |
| 7. Jeg vil anta at folk flest kan lære seg dette systemet veldig raskt.                                     | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>   |
|   | 1                               | 2                        | 3                        | 4                        | 5                          |
| 8. Jeg synes systemet var veldig vanskelig å bruke.   | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>   |
|   | 1                               | 2                        | 3                        | 4                        | 5                          |
| 9. Jeg følte meg sikker da jeg brukte systemet.   | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>   |
|   | 1                               | 2                        | 3                        | 4                        | 5                          |
| 10. Jeg trenger å lære meg mye før jeg kan komme i gang med å bruke dette systemet på egen hånd.            | <input type="checkbox"/>        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>   |
|   | 1                               | 2                        | 3                        | 4                        | 5                          |