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MASTER THESIS IN TELEMEDICINE AND E-HEALTH

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Visualization of contagious disease outbreak information for primary care physicians

Gudleif Aronsen

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Faculty of Science
Department of Computer Science
University of Tromsø

Foreword

Background

This thesis has been written as a part of a 30 ECTS master thesis, Inf-3996, for the degree of Master of Telemedicine and e-health at University of Tromsø (UiTø, spring 2007). Johan Gustav Bellika, my tutor, suggested this thesis. The subject is familiar to me, since I have been working on different projects together with the department of microbiology at the University hospital in Tromsø.

Acknowledgement

Writing this thesis has been a tough process. It has demanded a lot of work, patience and been time consuming. During this process it has been necessary for me to seek guidance and support from others. First of all I want to extend my gratitude to Johan Gustav Bellika, who has gone through this report several times. He has corrected me and shown me the right path in a fantastic manner. I would also like to thank Gunnar Hartviksen and Gunnar Skov Simonsen, who has been my supervisors and given me good advice whenever it has been necessary.

I also want to give a special thank you to Monika Alise Johansen at The National Center for Telemedicine. She has entered my process at the right time and has managed to keep me afloat during a difficult time. She helped me get started with the surveys and to produce the questions used in the interviews.

This assignment would never have been produced if my employer had not given me the time off work that I needed to complete it. They have also aided me with the financial means during my education. I want to thank my employer aswell for giving me this opportunity.

Last but not least, I want to thank my wife Eirunn Østeig and my children for keeping up with me during a period that has left them on their own during a period when I had to use all my time and effort on my studies. It has been a time where I have had to postpone many things, which should have been done. I hope I now can be able to catch up on many of these things.

Finally I would like to thank all my colleagues and classmates for being bearing with all my questions for help and assistance during this period.

Thank you all very much

Gudleif Aronsen

Abstract

This thesis is a part of an ongoing project at NST. This ongoing project has the intention to make a system for early detection of contagious diseases based on symptoms and diagnosis. The main goal of this project is to develop a system that will help detect outbreaks of contagious diseases. The system intends to create a logic model based on collected data from symptoms and diagnosis entered into the primary health care physicians electronic health record system. They will again exchange data with other medical offices and their electronic health record systems. From the information extracted from all electronic health records, the system will try to detect outbreaks of communicable diseases and send out warnings. The thesis I have perform:

1. Try to find out where the primary care physicians collect the information from and how the primary care physicians in future want to collect information related to contagious diseases.
2. Try to find out how the primary care physicians wants the information from the system, that send out messages about probability of contagious disease outbreaks, can be presented.

In order to reach these objectives, I have interviewed five primary care physicians, where one of the physicians has responsibility for preventing contagious diseases in a municipality. From the information gathered during the interviews this thesis present some pre-requirements that are needed before a pilot phase. In additional this thesis thru a presentation of possible visualization, present how the visualization of information in a future system can be presented for the primary care physicians. The main conclusion the thesis present is that the physicians want a system that is closely integrated with their own electronic health record system, that present the messages in a easy way with short messages that do not interrupt during patient consultations. The new system also has to be configurable in a way that the physicians themselves can decide when the messages should appear. The project also wanted to recruit as many primary care physicians as possible, to continue to take part in developing the system.

The result we have showed that the physicians use Internet and do not use the information on NIPH frequently. The most obvious source of information was colleagues in the medical office. The physicians do not use and hardly know of the official web pages for reporting of contagious disease outbreaks.

This thesis also has showed that the primary care physicians have limited of time for doing research in a busy day in practise and they do not use Internet for searching for contagious disease outbreak, but rather use colleagues and other sources of information.

We concluded that the classification system that is in use in primary health care among physicians are not able to be use alone as detection of diseases and symptoms registered in electronic health record system in the medical offices. There are two solutions to this problem, one is to alter the existing system of classification, the second solution is to use

physician’s habit to make notes inside the system and extract these to the new system.
And finally all physicians we interviewed are willing to contribute in pilot-phase in order to develop the system.

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List of abbreviations

NOKLUS	Abbreviated from Norwegian as "Norsk Kvalitetsforbedring av laboratorievirksomheter utenfor sykehus". An organization that have most of the medical offices that include the laboratory functionality services.
KITH	Abbreviated in Norwegian as "Kompetansesenter for IT i Helse- og sosial sektoren AS". In English "Norwegian Centre for Informatics in Health and Social Care".
NIPH	Norwegian Institute of Public Health
MSIS	Norwegian Surveillance System for Communicable Disease.
SIIDC	Swedish Institute for Infection Disease Control (SMI) or "Smittskyddsinstitutet" in Swedish.
WHO	World Health Organization
SARS	Severe Acute Respiratory Syndromes
SBDS	Symptom Based Disease Surveillance. System for symptom based disease surveillance in North Norway Health Region where primary care physicians will share information about communicable diseases.
TTL	Tromsø Telemedicine Laboratory
RODS	Real-time Outbreak Disease Surveillance
NORM	Norwegian surveillance of antibiotic resistance on micro organism
EARSS	European Antimicrobial Resistance Surveillance
HUS	Haemolytic uremesik syndrome
TAM	Technology Acceptance Model
TRA	Theory of Reasoned Action

Chapter 1

1 Introduction

1.1 Epidemic – diseases

The focus on health and health issues is increasing. The development within the healthcare services in Norway has been huge the latest 20-30 years. The focus on epidemiology has received more focus than ever. More and more countries have become aware of the dangers of outbreak of contagious diseases that can spread across country borders, from one continent to another. This has been highly focused in media and has become a real threat when it comes to the avian influenza. Many animals can be hosts for diseases that may be dangerous for humans.

1.1.1 Epidemic worldwide

One outbreak that chocked the world was the SARS pandemic (Severe Acute Respiratory Syndromes) in 2003. The WHO (World Health Organization) declared that SARS was a global threat. During some months there was registered infected and deaths caused by SARS in China, Canada, Hong Kong, Singapore and Vietnam(WHO 2003) Most countries in the world feared a SARS pandemic.

The other pandemic that has affected countries from the Far East to central Europe and even the Scandinavian countries is the avian influenza or the bird flu. Avian influenza is an infectious disease of birds that cause influenza on birds. A virus causes this flue. This virus has been transformed to other versions that can cause death of humans. This flu normally affects only birds, but in 2005 the first incidences of the H5N1 virus was confirmed in human in Cambodia and later in other countries. (China, Turkey, Iraq) (WHO 2003) These threats lead to many actions to stop the flu from spreading to chickens in the farming industry in Europe and Scandinavian. Actions like not keeping chicken outdoors in fear of spread of the flu from wilds bird in order to stop the pandemic spread of the disease.

1.1.2 Epidemic in Norway

The history of Norway has had and still in some part are scattered spread settlements. There are small villages and cities with less communication. This could have had a reducing effect of contagious diseases. However, there have been several epidemic outbreaks of contagious diseases in Norway. One of these was the Spanish flu in 1918-1919 that killed between 13000-15000 human lives. It affected all kind of citizen of the country. This disease was also a pandemic worldwide (Borza 2001).

In our nearest past we have had other epidemics in Norway. Autumn 2004 the citizens of Bergen got infected by "Giardia" and got ill by drinking contaminated water from the city's water supply. During this outbreak there was registered over 300 new incidences weekly in middle of November 2004. By the end of November 2004 more than 1100 citizens was infected with this organism. Figure 18 show the number of registered incidences of Giardia epidemic during a period of 13 weeks. Just a few incidences were registered outside this area (Biologer 2005). See section 2.6.3.1 for visualization from this report.

1.1.3 In modern times

Today the spread of contagious diseases are more in the headlines than just a few decades ago. The reason for this is diseases like HIV/AIDS, bird fly, Ebola Virus, tuberculosis, SARS, hepatises and many more.

There can be several reasons for more rapid spread of contagious diseases. Since the economy is better than ever, people are travelling more. Also the price for a flight tickets has decreased during the last years. This encourages citizens to travels more. This affect the way diseases spread. Other reasons can be that people using Internet to shop from all over the globe perform shopping worldwide. The packages can contain material that is spreading diseases. Also there are more ships in the shipping business, because people are buying more over the Internet and more cargo is shipped. The ship use water in ballast tank to make the ship more stable in the sea, depending on how much cargo they ship. These ballast tank can spread diseases from one area to another by loading the tank in a contaminated area and move the ship to another part of the world and unload the tank.

Food can spread contagious diseases, and since the food industry has become international, food is now shipped around the globe. Fish can be caught in Norway, sent to China for processing and shipped back to Norway or other countries. Because of all the shipping and processing of food, it can be difficult to determine where the food was contaminated. This has

happened with smoked salmon that have been farmed in Norway, processed in Poland and sold to Czech (Nettavisen 2007-02-10). In Norway we just have had a spread of contagious disease of Escherichia coli O157:H7 or also known as the Hamburger disease (CDC 2007).

1.1.4 Organization of health care in Norway

The health care service in Norway has three levels. The primary care physicians are at primary care level. The hospitals are the second level. The specialist levels are hospital like the university hospitals that have county and regional functions. In addition some hospitals have a national function that also is the specialist level. The level where most of the consultations are performed is the primary care level, where primary care physician are doing the consultations with the patients.

Countries in Western Europe are using more money on health care services than ever. In addition there will be a huge elderly population in the Western Europe a few years ahead. The elderly population does not have the same quality immune system as they had when they were younger. This makes them more threatened by contagious diseases and therefore has a higher risk of death if a contagious disease infects them.

If there is an epidemic outbreak of influenza or some other contagious disease, the workload on primary care physicians will increase. To meet the demands for consultations it is important that the primary care health level has an effective and good system to warn the practitioners that there is an outbreak as soon as possible.

Today the Norwegian Institute of Public Health (NIPH) is responsible for handling contagious epidemic diseases in Norway. This institute is delivering reports to the public health on which contagious diseases that are ongoing. The weekly reports from the institute are based on diagnosis from primary health care physicians and major laboratories at the hospitals. The major problem with the report from the institute is the frequency, which is one week, and that the incidence rate is reported on county level.

1.2 Background

There is an ongoing project that is called "Symptom based disease surveillance in The North Norwegian Health region" (SBDS). The projects goal is to investigate the effects of sharing information about communicable diseases. The hypotheses about sharing information between primary care physicians are that it will be:

- Possible to detect contagious disease outbreaks earlier
- Possible to make diagnosis and intervention earlier than today.
- Reduce the number of infected.
- Possible to reduce the total cost related to contagious disease outbreaks.

The SBDS project wants to develop a national and international surveillance system for communicable diseases in consensus with the Norwegian Institute of Public Health (NIPH). It has been showed that electronic reminders to perform syphilis screening have had an effect, especially if there where there was a warning regarding to the electronic health record (EHR) (Rosenman M 2003).
The SBDS project has two main objectives:

1. To distribute open source and free software system for disease surveillance and disease reporting.
2. To develop methods and models for calculation the risk of and early detection of outbreaks.

In the US there are many system for detection and warning of contagious disease outbreaks(Henning 2004). However, part of the problem is that just 9% of the population visits health institutions that reports to a surveillance system (Metzger, Hajat et al. 2004). In the north Norwegian health region we have the opposite situation. Nearly all of the primary care health centres or primary care physicians have an electronic health record system that can report this information, but no system exists that can extract or distribute disease surveillance data.

In Sweden there is a system that can give information about contagious diseases. However, the frequency of updating the information is once a week (Rolfhamre, Grabowska et al. 2004), which reduces the validity of the data as information source for primary care physicians. There is also a usage problem because the primary care physicians have to seek and find the information they are looking for. This is reducing the value of the information.

1.3 Problem definition

This master thesis was written to provide input on how to visualize patterns of communicable disease for primary health care physicians. The major reason for doing this was that we wanted to find visualisation methods that could help us build a symptom based surveillance system. The symptom based surveillance system may help physicians discover local disease outbreak. The information in the symptom based surveillance system is collected from primary care physicians, laboratories and local health authorities involved in infectious disease prevention.

This thesis work was done within the Tromsø Telemedicine Laboratory (TTL) project symptom based disease surveillance in the north Norwegian health region (SBDS). This project investigates whether the distribution of information related to communicable diseases among primary physicians changes the clinical practise with regard to testing, diagnosis and treatment of contagious diseases.

This thesis investigates how the primary care physicians collect and from where they collect information related to contagious diseases. The thesis also try to find out how primary care physicians wants the information from a future contagious disease outbreak system can be presented.

Therefor part of this thesis is to get feedback on different visualization techniques from primary care physicians. In addition we collected information about what kind of information they base their decisions on today, and how they get access to this information. The results from the interviews will be used to make requirements for the SBDS system.

We have broken this question down into smaller related sub problems, which collectively can give us the answer:

- Where do the physicians find information about contagious diseases today and how do they want to find the information in the future?
- How do the physicians use the information, how often do they use it, and how relevant was the information?
- How do the physicians use the local EHR system to record information about the patient and how will this affect the new symptom based surveillance system?
- What kinds of diseases are most suitable to use in the test phase?
- What kind of information is most relevant and valuable to present in the new symptom based surveillance system?
- How often do the physicians want to see information from the new

SBDS system?

An other goal of this thesis is to attain, as far as possible, we tried to recruit as many primary care physicians as possible, to continue to take part in developing the new contagious diseases outbreak system.

1.4 Delimitations

There are several delimitations on the scope of this study. First of all we had to limit the number of physicians we interviewed. The reason for this was the limited time available to do the study. The interviews were done in cooperation with Monika Alise Johansen.

All medical offices in north Norway have an electronic health record system, but have no electronic system for exchanging messages when there is an outbreak of contagious diseases. An electronic system for detecting outbreaks of contagious diseases has to be buildt up from scratch. Therefore all visualization of contagious disease patterns used in the interviews had to be presented as a possible future system. The visualizations we used during the interviews with the primary care physicians were in the following situations:

1. The primary care physicians receive messages of contagious disease outbreak during a consultation.
2. The primary care physicians receive messages of contagious disease in the office without consultation or just when the physicians are off duty.
3. The other situation is when the primary care physicians during a consultation with a patient need information about current contagious diseases in the patient population to make a decision about diagnosis or treatment.

We focus on a limited set of contagious disease situations:

1. We will focus on contagious diseases that are reported to MSIS by primary health care doctors. Specific contagious hospital diseases in-house are not taken into consideration. The reporting from hospital to MSIS based on specimens from primary care health doctor will be included
2. Reporting to and from the Norwegian Food Safety Authority is not included in this report.
3. When there is an outbreak of contagious disease in local area, messages are sent to each medical office or physicians.
4. When there is a contagious disease outbreak we focus on the system today in order to follow the information flow.
5. The patient is left out of the information flow.

Other determination of concern

The time given for the study is limited. Due to the intention of the course it is limited to 600 hours.

The length of this study does not allow to studying the use of visualization

on large scale as all primary care physicians in the north Norwegian health region even if we wished. We will only be able to include a fraction of primary care physicians.

In this study the requirements and results are based on the results from the interviews with the physicians.

1.5 Methodology

The problem definition is normative for the choice of research method and investigation plan. The choice of research method is also a choice of how to approach the problem definition.

The number of physicians that will participate in the investigation is limited to 5 physicians. In this thesis we will use a qualitative analysis rather than a quantitative analysis. The reason why this method was chosen is that this gives answers to why the physicians use official NIPH report or not use them at all. The physicians can also provide answers to how a new system of disease detection can work. The physicians can also give us a list of diseases that are most likely to look for in a pilot and data collection phase. The physicians gave us a direction on what kind of visualization that will be preferred. In the end, we got enough information to get an idea on how the physicians wanted information presented in a new system. We also got to know whether the physicians were interested to participate in developing a complete system for detection contagious disease outbreak.

In this thesis we have broken the amount of work that has been used to create the thesis into the following structure:

- Get an overview of the research area and main question to answer
- Formulating the problem definition
- Establish limitations to confine the problem definition
- Establish contact with primary care practitioners
- Collecting data and structure the data collected
- Analysis the results
- Draw conclusions

1.6 Major Results

This thesis has showed that the primary care physicians have limited of time for doing research in a busy day in practise and they do not use Internet for searching for contagious disease outbreak, but rather use colleagues and other sources of information. In additional the physicians receive information from laboratory on sample that is confirmed with contagious diseases. Together with the laboratories results the laboratories also send a paper report from MSIS to the physician. The physicians add additional information and send the report as an ordinary letters to the Norwegian Institute for public health. The physicians do not use and hardly know of the official web pages for reporting of contagious disease outbreaks.
We also showed that the classification system that is in use in primary health care among physicians are not able to be use alone as detection of diseases and symptoms registered in electronic health record system in the medical offices. There are two solutions to this problem, one is to alter the existing system of classification, the second solution is to use physician's habit to make notes inside the system and extract these to the new system.
The most likely diseases to include in a pilot phase are the most usual diseases as pertussis, meningitis, legionnaries´disease and other respiratory diseases.
In the new system for contagious disease outbreaks detection where the physicians share the information across the medical offices, there have to be a lot of trust in information relevance and validity. The physicians' wants the information presented in their own electronic health record system (EHR), an application whitch is in use daily. By using simple coloured messages with short text visualized thru pop up function, will bring the information fast and easy to the physicians. Additional functions for future exploration of the messages will gain the system.
The visualization convinced us that the physicians will contribute to deploy the new system if the information are easy to access, easy to use and do not interrupt consultation with patients. The system also needs to be configurable and give useful information related to the outbreak that takes a minimum time to access. The physicians are willing to contribute in pilot-phase in order to develop the system.

1.7 Outline

The structure of this thesis is as follow:

- **Chapter 2: Information and visualization of medical Information.** This chapter show how reporting of contagious diseases is today and the characteristics of surveillance system today. It shows how visualization reports of communicable diseases have been and is today together with examples. It describes some techniques of how physicians make decision.
- **Chapter 3: Methods and Approach.** This chapter show which methods we used for collecting information and how we performed the interviews with the physicians. There is also theory on how interview techniques should be used and how we used them.
- **Chapter 4: Requirement.** The requirement from the physicians we collected during the interview is organized in this chapter.
- **Chapter 5: Results.** This chapter contains the result form the interview of the physicians from primary care.
- **Chapter 6: Discussion.** This chapter tries to assess which goal where reached as a result of the research and the problem we can see related to the project.
- **Chapter 7: Concluding Remarks.** This final chapter deals with the main conclusions of this thesis and areas that could be interesting for future work.
- **Appendix A:** Overview of the diseases that is reported to MSIS, group A.
- **Appendix B:** Overview of the diseases that is reported to MSIS, group B.
- **Appendix C:** Overview of the diseases that is reported to MSIS, group C.
- **Appendix D:** The form used to report to MSIS for Group A.
- **Appendix E:** The consensus declaration we sign with the physicians we interviewed.
- **Appendix F**: Contains the question we used for the interviews with the physicians.
- **Appendix G**: Show the PowerPoint slide show used for visualization during the interviews.

Chapter 2

2 Information and visualization of medical information

2.1 Introduction

Today many physicians use different information sources to support their decisions during consultation of patients. The physicians use the sources along with information to find the correct diagnosis for patient. With contagious diseases it can be hard to find relevant and valuable information the physicians need during consultation.
This chapter will show which systems are available for physicians and the information they visualize. It also contains information on how physicians make decisions during consultations.

2.2 Norwegian Institute of Public Health (NIPH)

2.2.1 Short history

The new institute was established January 1 2002. This was done when the former National Institute of Public Health, National Health Screening Services, the Medical Birth registry in Bergen and the Department of Drug Consumption Statistics and Methodology from the Norwegian Medicinal Depot was fusion into one unit. But all these former fusion partners have a history of their own.

2.2.2 Goal of the institute

The Norwegian Institute of Public Health is a national centre with the main goal of improving public health (NIPH 2007). This is done by focus on promotion and preventive issues. This institute also has expert knowledge of epidemiology and infectious disease control.

2.2.3 Organization chart

Figure 1 shows the different divisions of the NIPH, and the division of Infection Disease Control is what we have in focus.

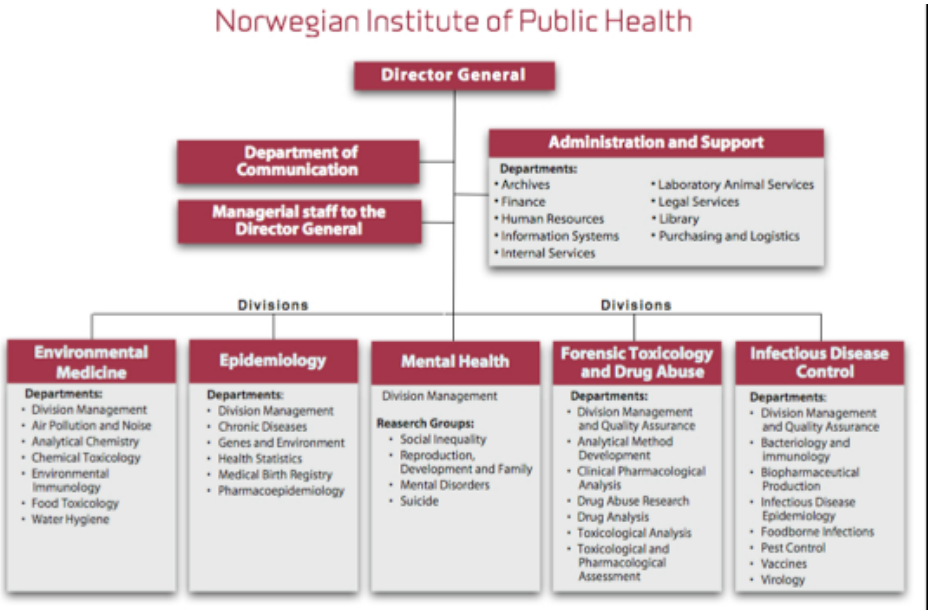


Figure 1 Organization Chart 2006 of NIPH Ref. http://www.fhi.no

2.2.4 The NIPH homepage

The NIPH homepage provides information about studies, reports, newsletters, information from departments and health development.

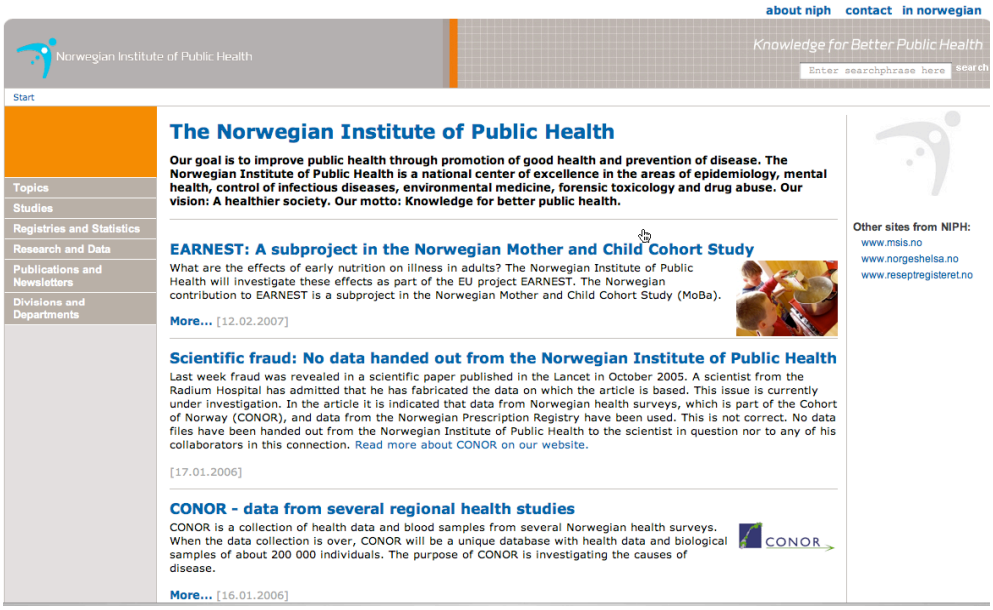


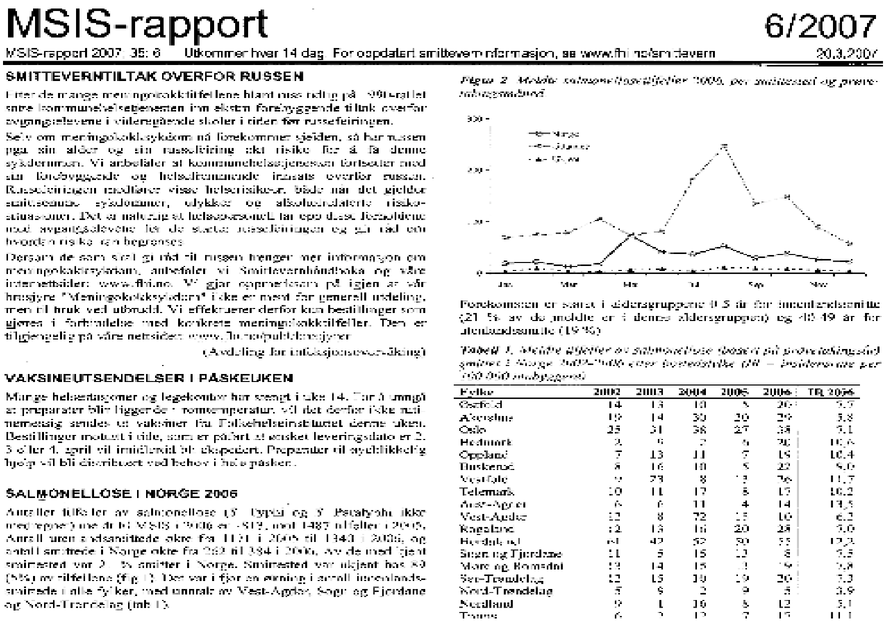
Figure 2 Part of homepage of NIPH. (http://www.fhi.no/eway/?pid=238- English version, http://www.fhi.no - Norwegian version)

Figure 2 show the home page of NIPH. This page will just guide the user to

next pages. This page contain information in general.

2.2.5 The MSIS-Report (Norwegian Surveillance System for Communicable Disease)

Among many functions the institute has, there is one in particular that we are interested in, the MSIS-report. This weekly report publishes information generated by the national surveillance system for communicable diseases. The report focus on different issues every time, but it often contains statistics that help the reader to see historical infections, different used diagnosis on different illness. The report have for a long time been printed on paper, but it can be downloaded from http://www.fhi.no (http://www.fhi.no/eway/default.aspx?pid=233&trg=MainArea_5661&MainArea_5661=5618:0:15,1327:1:0:0:::0:0) WebPages as PDF-document. The problem with this page is that it is not easy to find from www.msis.no or www.fhi.no. Figure 3 show part of the MSIS paper report nr 6 of 2007.


MSIS-rapport 6/2007

MSIS-rapport 2007; 35: 6 Utkommer hver 14 dag. For oppdatert smitteverninformasjon, se www.fhi.no/smittevern 20.3.2007

SMITTEVERNTILTAK OVERFOR RUSSEN

VAKSINEUTSENDELSER I PÅSKEUKEN

SALMONELLOSE I NORGE 2006

Figure 3 Part of scanned report from NIPH. Published every week.

2.2.6 The MSIS Homepage

This homepage (www.msis.no) is a homepage where users can find statistics on communicable diseases. Figure 4 is part of MSIS homepage. The statistics is founded on analysed specimens. Laboratories and doctors in Norway notifies to MSIS (central unit of Norwegian Institute of Public

Health) of certain diseases. All statistics are historical. The institute is updating the data on daily basis on the report from the informers. The reports are holding information on each disease or diseases in county/municipality.

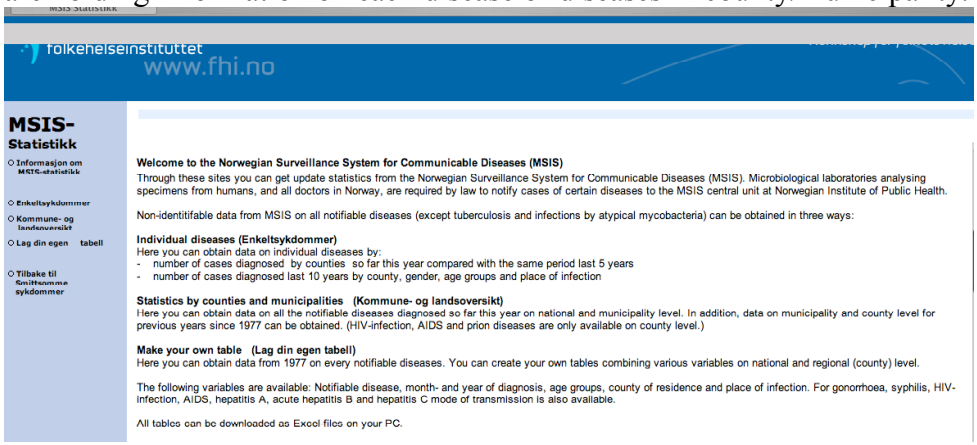


Figure 4 - part of MSIS homepage. Ref: www.msis.no

This home page is the major front page for users to get information about the statistics around each specific diseases or county or municipality.

2.2.7 Reporting to NIPH

The main way to report to NIPH (MSIS) is to use paper. NIPH have also one other channel for reporting. The www.utbrudd.no is an electronic reporting channel.

The reporting system of NIPH

The reporting system is the governments reporting system of contagious diseases. The reported data are used to generate statistical information for the public. The data is based on reports from medical-microbiological laboratories and physicians. Some data are anonymous (NIPH 2007). The laboratories that report to MSIS have three different ways to report incidences depending of what kind of disease (Appendix A). The three different ways of reporting contagious diseases are:

- Group A – Individual report. Reported from doctors and specialized microbiological laboratories at hospital on a form. All patients are identified and reported. There is also a report sent to the head doctor in the patient's municipality. In this group there are more than 50 different contagious diseases. See appendix A. The form of report is in Appendix D
- Group B – Anonymous report. Reported from doctors and specialized microbiological laboratories at hospital on patients without any name or birth of date. List of diseases is in Appendix B.

- Group C – Summarized report. This report is just a summarized report on the different diseases in Appendix C.

The technological testing equipment in the primary care office is getting more and more advanced. There have been tremendous developments in the polymer chain reaction (PCR) testing technology, which uses DNA-material to detect bacterial infections and is able to detect the exact specific kind. This PCR equipment has previously been used only in hospital laboratory. However, in the future this technology will be used in primary care offices if/when it becomes less expensive. This development can affect the whole system of reporting to MSIS. The report to MSIS from the laboratory at the hospital has been the foundation for the surveillance of contagious diseases in Norway. This new way of analysis by primary care physicians' office can in the future undermine the MSIS system.

2.3 Epidemiology and visualization

2.3.1 What is epidemiology

Epidemiology is defined as the study of distribution of health related events in a specific population. It also include the study to control health problems(Moyses Szklo 2004). It is also the study of how diseases are spread and about the diseases(Bengt Lundh 1990). An epidemic is limited in spreading. If an epidemic is spread over several country or big area it is called a pandemic(Elvy K Røkke 1983). Some of the best knowned epidemic diseases in history are cholera, plague, the Black Death, measles, diphtheria, spotted fever, typhoid and Spanish influenza. The epidemiology need not just to be about rapidly spread diseases. It can also include diseases that take a long time to develop. In the industrial world or the most developed countries like US, UK or other western countries, there have been an epidemic development of heart diseases or cancer since the 60´s(Roberts 1978).
The WHO (World Health Organization) is warning every country in the world, if there is an epidemic outbreak. The surveillance in Norway is done by the Norwegian institute of public health(Elvy K Røkke 1983).
In order to prevent outbreak of diseases or to handle sudden outbreaks of diseases, researches are trying to develop methods of detection to detect outbreaks before there is one or to treat patients that have been infected by contagious diseases. Even if epidemiology is about health and illness in a population, it comes down to every individual and his doctor that makes the decision about treating a condition when needed and actions as a

consequence of an epidemic disease outbreak.

All information is history after just it is said or read. But some old information can be new and some new information can be old depending of the individual that are receiving it. This is making the grounds different for each individual in the society. This affect the way we do things, the way we speak, the way we act, and the way we think.

2.3.2 The father of modern epidemiology

John Snow (1813-1858) is considered a pioneer in modern epidemiology. He showed that there was a correlation between the water pumps used as drinking source and deaths caused by cholera in London. He was able to show that people around the water pump in Broad Street died during the cholera breakout in 1848-1854 and that there were most deaths around this water pump. He used a map similar to the one shown in Figure 5 to indicate where in the local community there was an outbreak and was able to identify where the contaminating source was. He also showed that people that used Southmark and Vauxhall Water Company have higher mortality rate then other water suppliers in London. This can be seen in Table 1(Newsom 2006).

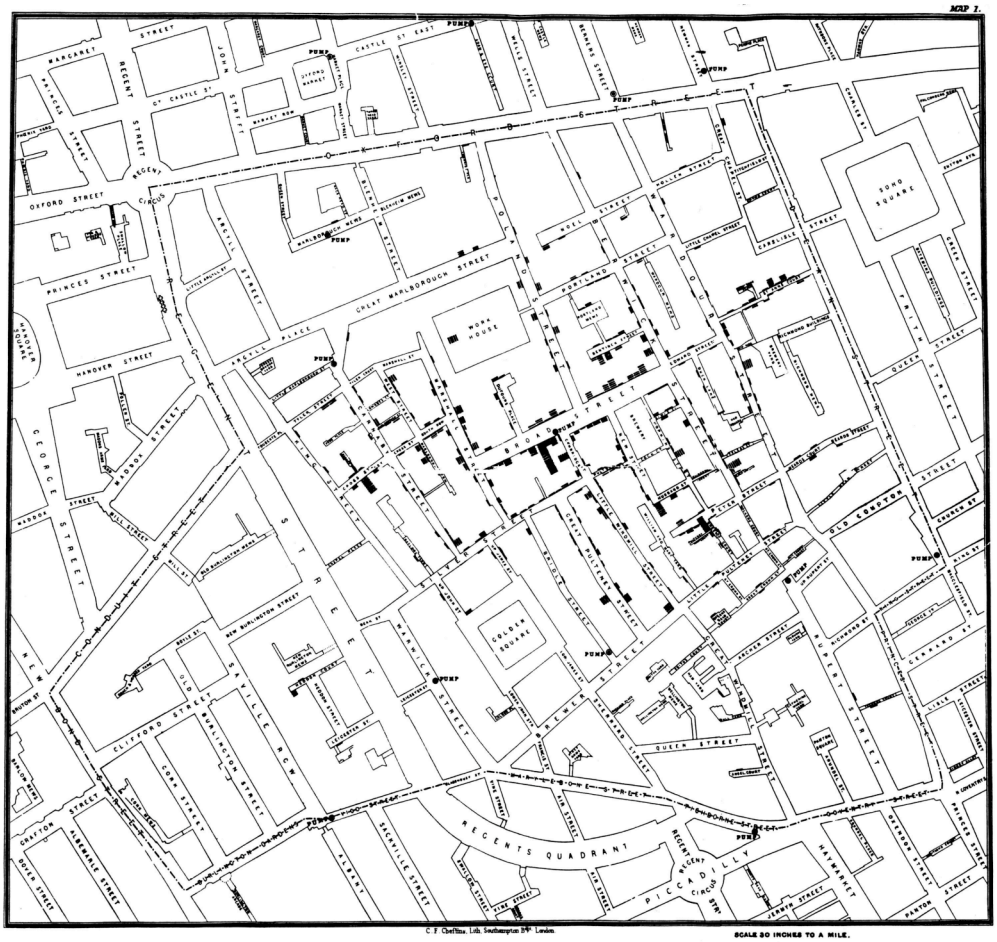


Figure 5. Snow's map. Black lines indicate deaths. This is a good example of visualization.

John Snow is considered as a genius in the field. He achieved to develop theory concerning mechanisms and processes in his chosen study. John Snow used published practical suggestion to prevent outbreak of cholera. He used every sources available to inform and did not restrict to any method(Cameron and Jones 1983).

	Number of houses	Deaths from cholera	Deaths per 1000 houses
Southwark and Vauxhall Water Company	40046	1263	315
Lambeth Water Company	26107	98	37
Rest of London	256423	1422	59

Table 1 Snow's analysis of water. An example of visualization.

When John Snow used a combination of map and tables, he showed that this can be used for detecting disease outbreaks.

2.4 Surveillance systems

There are many surveillance systems for detection of contagious disease outbreaks. These systems have different approaches on how to detect contagious diseases. Many systems are collecting information from different sources. Sources can be medical drug stores, analyzing absenteeism, hospital information on admittance or consultations at hospital and many other sources.

We can divide the surveillance system into four broad categories.

Syndrome surveillance systems were mainly developed in the US after the bio terrorist attack in 2001 where anthraxes were mailed to different media offices. These kinds of systems got more focus after this event.

System for contagious disease reporting based on laboratory results. The systems are basing the surveillance on the specimens that are analyzed and found to contain contagious micro organisms, both in human and nonhuman specimens. These laboratories are often hospital laboratories, equipped with modern equipment and highly qualified and trained personnel.

The third kind of surveillance systems is the sentinel systems. In the Norwegian system there are over 200 medical offices that report. There are two kinds of reporting. One group is reporting incidences; the other group is taking samples of the incidences and gets these samples examined.

In addition we have surveillance of drug resistance among the micro organism that is identified. These are particularly related to bacteria that develop resistance against antibiotics. Many bacteria become resistant against several antibiotics.

Surveillance systems are trying to detect outbreak as early as possible. The different systems are trying to achieve this in different ways. There are three parameters that affect how early the outbreak can be detected (Buehler 2004). The first issue is the reporting of data to a system. All data have to be correct and valuable. The sources that report data are typical health departments, medical offices, health care facilities and laboratories. The reporting also have to be done as fast as possible in order to be valuable to the users of the surveillance systems. Second, the analysis and recognition of pattern that indicate outbreaks need to be improved. This can be done in different ways, but in the end have to face the real world and give the correct message at the right point of time. The third issue is the new indicators of outbreaks as new types of data as; prescriptions, health-care product

purchases, absences from work or school, presenting symptoms from health care providers and laboratory test orders.

2.4.1 RODS (Real-time Outbreak Disease Surveillance)

2.4.1.1 Introduction

Historically the public health community has relied on watchful eyes of doctors, who have reported cases individually or clusters of particular diseases to authorities. But can these days be gone? Can the availability of electronic health care data and more automated detection system detect outbreaks earlier and interment outbreak of diseases or bio terrorism?

2.4.1.2 Tragic event

Due to recent tragic event in use of biological organism to cause death among public victims in US, the work with such system have been taken into consideration, and the lack of preparedness has been highlighted for biological atacks but also natural disease outbreaks(AS Khan 2001; OTool 2001; TV. Inglesby 2001).

2.4.1.3 Goals of RODS

The primary goals of this system are to prevent diseases in the community. Preventing disease, having knowledge of existing disease, incidents rates, the effectiveness of preventive measures, does this. However, most of the disease surveillance systems are passive and rely on practitioners voluntarily reporting to the public health system(TV. Inglesby 2000).

2.4.1.4 Expectations for health indication surveillance systems

There are several indications that can lead to detection of bio terrorism and outbreak of diseases. A group of expert had a workshop on describing a system, which should have goals like facilitating rapid recognition of disease outbreak, improve data transmission and analysis speed, be capable of integration with other systems, provide additional information to assist during outbreak investigations, provide information on medical countermeasures as vaccines or antibiotics and historical and trend data used as baseline comparison and long-term monitoring.

2.4.1.5 Existing systems

Many agencies and municipalities have tried to improve their public health capabilities with novel and innovative approaches. Because of the different origin these system have similarities and differences. The systems use different data sources. Both sources of existing data and new information have been used. Comparison of the system has been published. These comparisons show that there is much work to be done, in order to get more efficient systems. Sharing information, knowledge and rethinking of concepts will perhaps in the future enable us to make better systems(WB Lober 2002).

2.4.1.6 Example of RODS and visualization

One of the systems that have been investigated in a workshop is the RODS from RODS Laboratory. These systems collect data mainly from hospitals and over the counter sales of drugs.

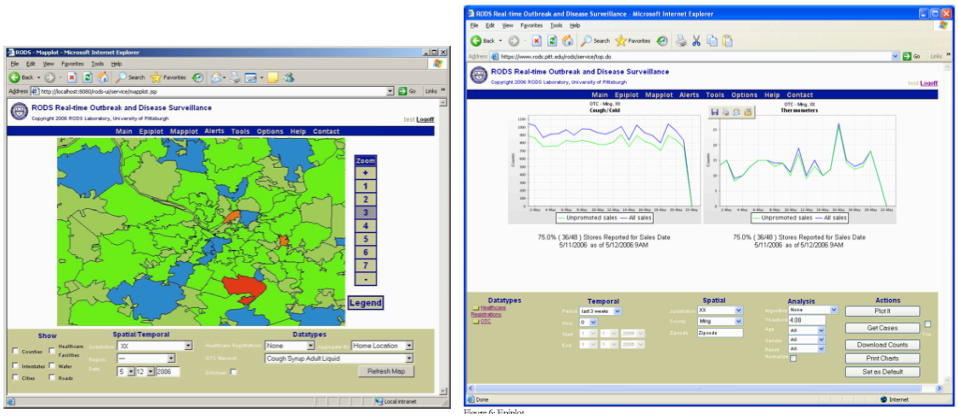


Figure 6 Show two different visualization from RODS by RODS Laboratory. Pictures from RODS Laboratory at http://rods.health.pitt.edu/

Figure 6 shows two different ways of presenting visualization in RODS. They contain many choice and option to navigate and alter the visualization. This can have advantages and disadvantages.

2.4.2 MSIS – Surveillance system in Norway

The reporting system of contagious diseases in Norway is dependent of information from several sources. Mainly the system is based on the results of the laboratory send to the primary care physician. However, cases can also be reported on suspicions. The receiver of the report in the end is MSIS that is under the Norwegian Institute of Public Health.

Figure 7 shows the reporting of contagious diseases in Norway when the

laboratories and primary health care physicians are involved. It also shows how the information flows.

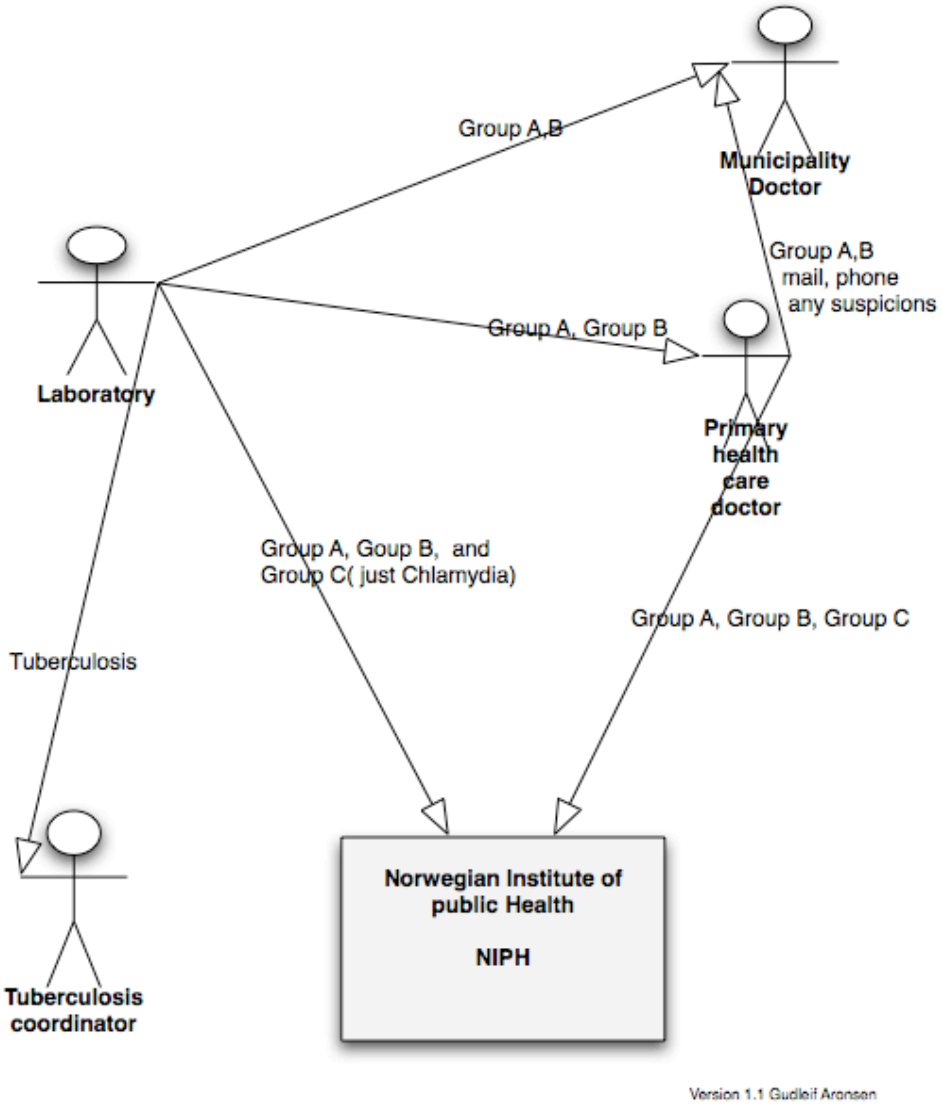


Figure 7 Flow of information from laboratories in hospital and primary care physicians. Show how different group of reports is reported. The laboratory will inform the municipality doctor, primary health care physicians and NIPH. The municipality doctor and the primary health care physicians have a statutory obligation to ensure that NIPH and others receive the reports.

The NIPH is also responsible for the web pages:

- www.msis.no
- www.utbrudd.no

NIPH have two dedicated web pages that are supposed to cover two different functions.

2.4.2.1 Group system of diseases

The different groups of contagious diseases have different routines for reporting. The groups are supposed to help manage the reporting of diseases and the frequencies.

Group A
Diseases in this group have to be reported individually, both in written form and verbal.

Verbal reports have to be done immediately. The written report has to be reported the same day on an approved form from MSIS. All reports have to include the patients name, address, and day of birth, and birth id. The reports from laboratories are sent to the requesting physician and the municipality physician. The diseases in this group are listed in Appendix A.

Group B
care have to report. The diseases in this group are listed in Appendix B.

Group C
This group contains two diseases, genital Chlamydia, influenza like diseases. The numbers of incidences of Chlamydia are reported once a year from laboratories. The numbers of influenza like diseases and the sex and age distribution are reported once a week during winter from the doctor's offices. The laboratories do not have to report this disease. This is called sentinel surveillance system.
The diseases in this group are listed in Appendix C.

2.4.2.2 North Norway

UNN HF´s (University Hospital of North Norway Trust) laboratory in Tromsø provide laboratory services for Troms and Finnmark County. The Laboratory at Nordland Hospital Trust in Bodø covers Nordland County. These two laboratories cover Northern Norway's laboratory functions for detecting and specifying the species of bacteria and virus in specimen from humans. These laboratories receive most specimens from primary health care doctors and institutions in Northern Norway.

2.4.2.3 Receiving specimen

When the laboratories receive the specimens, doctors and laboratory personnel decide how to proceed and examine the specimens based on the request and the information attached to the request.

2.4.2.4 Outbreak of contagious diseases

If the incidence rate of a contagious disease in an area is higher than expected, it may be an indication of an outbreak. How many incidences that is required to use the term "outbreak" depends on several conditions. In some situation only one or two incidences is enough to call it an outbreak. In other situations we need more incidences to call it an outbreak.

The diseases spread differently. This depends on whether the micro organism spreads thru air or water. Therefore the physicians need knowledge on how the diseases spread. By knowing this the physicians can help the patients to avoid being contaminated during an outbreak. However, this information will often get distributed thru television, radio and other media.

2.4.2.5 What to report to MSIS

The laboratories at the hospital have a statutory obligation to report incidences of contagious diseases to MSIS. Contagious diseases are defined as general dangerous diseases that are contagious, can appear frequently, have high mortality rate or give serious or permanent injuries as:

- Lead to lasting or long term of treatment, hospitalization, sick leave or convalescence.
- Diseases that can have an extensive effect on public health.
- Diseases that have no effective treatment or protection that leads to extensive workload on health care services.

2.4.2.6 Who should report to MSIS

All physicians, even if the physician are off duty, have an obligation to report if they discover or have suspicion of disease of group A diseases defined by MSIS.

2.4.2.7 The reporting system of contagious diseases

MSIS is the official institute of surveillance of contagious diseases and is administrated by NIPH. The purpose of reporting system is to be able to issue warnings and preventing contagious disease outbreaks.

2.4.2.8 Statutory reporting from the laboratories

All laboratories must report all cases of diseases within group A thru C. It is the medical responsible doctors at each laboratory that have to see to that all these reports are send to MSIS. The report has to be reported even if primary care health doctor reports the incidences. In addition, the responsible medical doctors at the reference laboratory have a statutory obligation to

report to MSIS even if the report is send by other laboratory. The reporting system is based on different sources of reporting.
Positive tuberculosis has to be reported, even if the examination result is an atypical bacterium. The resistance examination will be carried out by NIPH.

For instance if a laboratory detects a patient sample containing the tuberculosis bacteria, they are obligated to report this to the MSIS and the primary care physicians.

In addition a report is also sent to a person that coordinates the treatment of patients in the municipality where the patient lives.

2.4.3 Sentinel system

Around the world there are many countries that have different sentinel systems. The differences are depending on which diseases they want to surveillance. The system contains mainly of three basic component activities:

- Data Collection
- Analysis
- Dissemination

The data collection activities are a process can be active or passive of nature. When the process is passive then there are some agencies that wait for someone to report cases. When the processes are active then the agency are looking up cases. All these processes can be done electronically or manual.
The analyses are to process the incoming information and decide to make action in order to protect public health. The process of information can be with computers that are programmed with experts in the area.
Dissemination of the information to those who need to know must be done timely (Losos 1996).

2.4.3.1 Sentinel system in Norway

The NIPH have a special system for reporting influenza and influenza like diseases. These are the Group C. The system is divided in two:

- One part of the system is surveillance influenza thru influenza like diseases where the physicians report this to MSIS. All in all there are 201 medical offices that reports.
- The part of the system are collecting samples and trying to identify influenza virus. Participation from the physicians is voluntarily.

The reporting is send weekly to MSIS. The Figure 8 is showing an example of this report.

MSIS VAKTTÅRNSYSTEM FOR INFLUENSAOVERVÅKING 08/05/2007
Andel (%) legekontakter for influensaliknende sykdom av alle legekontakter,
Norge totalt og helseregionene, de siste fire epidemiologiske ukene

	Total	Øst	Sør	Vest	Midt	Nord
Epi uke 15	0.7%	0.5%	0.7%	0.7%	0.8%	0.8%
Epi uke 16	0.5%	0.5%	0.5%	0.5%	0.5%	0.7%
Epi uke 17	0.4%	0.4%	0.3%	0.4%	0.4%	0.6%
Epi uke 18	0.3%	0.3%	0.4%	0.2%	0.3%	0.6%

Helseregion Øst: Østfold, Akershus, Oslo, Hedmark og Oppland.
Helseregion Sør: Buskerud, Vestfold, Telemark, Aust-Agder og Vest-Agder.
Helseregion Vest: Rogaland, Hordaland og Sogn og Fjordane.
Helseregion Midt-Norge: Møre og Romsdal, Sør-Trøndelag og Nord-Trøndelag.
Helseregion Nord-Norge: Nordland, Troms, Finnmark og Svalbard.

Influensaaktiviteten er under den grensen vi har satt for influensautbrudd

Figure 8 show the influenza report (Group C) in the original paper report from MSIS.

Figure 8 is a simple report. It is easy to read. Since this is inside the paper report, it is well known for the physicians. This can be a reason that the medical office voluntarily sends in samples for identification of the influenza virus. (NIPH 2003)

2.4.4 QRESEARCH

Introduction

In UK there is an collaborative project between Health Protection Agency (HPA), University of Nottingham Division of Primary Care and EMIS (EMIS 2007) where they have developed a national primary care-based early warning system for health protection. Data from primary care physicians was collected along with prescriptions. There are several other systems that provide information on illness in community as NHS Direct and RCGP (Royal College of General Practitioners). Where these systems provide information on national and regional levels and none of these are providing information on acute morbidity in community level.

Description of the system

During 2002 EMIS created a new primary care-derived database. This is called QRESEARCH. The goal of this product was to perform research and health analyses and run as a non-profit-making venture. The system contains data on health needs, risks, care and outcome, for a population of about 3.8 million patients. The system contains national representatives of 525 volunteer practises, where some have over 16 years of historical data.
All patient sensitive information in the database has been anonymized. Several authorities have approved the system(Smith, Hippisley-Cox et al. 2007).

During the pilot phase, the project developed a set of key conditions to map health protection problems. Among these condition the prescriptions was aggregated into a set of "Read code" system (Read code are classification system for general practitioners and health protection epidemiologists in UK)
Consultation data (first and new episodes only) was extracted weekly from the database and analysed. A weekly bulletin was produced summarizing the activity and compared with equivalent week of the previous year. The bulletin was distributed among health authorities level that worked in public health. The system has been able to produce timely data on illness at local level and to link prescribing to morbidity.
The project has the intention in the future to develop information on daily based local influenza information which is needed in an influenza pandemic(Smith, Hippisley-Cox et al. 2007).
Existing system for primary care surveillance system are not able to provide data on the level and nor can they provide timely data linked to prescribing. The QRESEARCH have automated its extraction and routinely generate coded data. The system has intention to extract and analyses data on daily basis from general practice.

2.4.5 Drug resistance epidemiology

2.4.5.1 Introduction

Human have used plants and other substances found in nature in treatment. This has been done in much of the indigenous population. If the treatment was effective or how the treatment worked, was not focused on.

2.4.5.2 Definition

Antibiotic is a chemical substances that is produced by different types of micro organisms and this antibiotic is reducing or stopping growth of other micro organism. The antibiotic substances we use today are produced in laboratories.

2.4.5.3 Short history

Until the 20 century, there was no medical treatment for infectious diseases. There are examples of using other substances based on arsenic. In the end of 19 century and in the beginning of the 20-century it was proved that several antibacterial substances had an effect on bacteria. In 1941 Howard Florey and Ernst Boris Chain managed to concentrate penicillin and inject it into a patient.

2.4.5.4 Reporting resistance

All antibiotic treatment needs to be given in enough concentrations in order to be effective. To determine the level of concentrations of antibiotic, this have to be done in vitro and the term that is used is MIC (minimal inhibitory concentration), n normally given in mg/l (γg/ml). To classify the sensitivity, two groups of classification have been used: a 4-group system and a 3 group system. The groups are specified like this:

- 4 group system.
  - Sensitive – effect on normal concentrations
  - Moderate sensitivity - effect on high concentrations.
  - Relative resistance – effect on extreme high concentrations
  - Resistance – no effect
- 3 group system.
  - S – Sensitive, effect on normal concentrates
  - I – Intermediate, effect with high concentrates
  - R – Resistance, no effect

The four-group systems have been used in Norway for a long time, but the laboratory use now the 3-group system.
To treat a patient, there have to be an identification of micro organism. The resistance test should be performed in order to determine which antibiotic and what concentration that can be used. This information can be vital information for the physicians in order to treat patient.

2.4.5.5 Developing resistance

The micro organism can develop resistance against anti-biotic the natural way or adopted. This has happened in several incidences. Just after the new penicillin was taken into use, the presence of resistance micro organism was discovered. In 1949 40% of the Staphylococcus in Boston had developed resistance. The penicillin was first given in low doses. Raising the dose was the thing that was done first. After some years the micro organism developed resistance against penicillin. The history repeats itself, the same thing has happened with several medications used as anti-biotic treatment.

In 1959 there was an outbreak of diphtheria in Japan, and after a while all the diphtheria bacteria was resistant against several antibiotics. In addition, they also found Shigellosis diphtheria and Escherichia coli that also were resistant to several antibiotics.

2.4.5.6 Organization of surveillance of resistance in Norway - NORM

NORM (Norwegian surveillance system of antibiotic resistance on micro organism) is the institution in Norway that is responsible for surveillance of antibiotic resistance in micro organism.
NIPH is responsible for data processing, which is done at the University hospital of North Norway. NIPH cooperates with the experts within the field to select witch micro organism and antibiotics that should be monitored.
The purpose of NORM are to collect and process data regarding the resistance of micro organism, doing research, inform the public and contribute to provide Norwegian health authorities with information(Lovdata 2007).

The resistance epidemiology is monitored continuously and reported to MSIS every fourth month. All the physicians in counties and municipalities that have responsibilities regarding surveillance of contagious diseases receive reports very year. All laboratories have responsibility to surveillance constants their own county. There also is established a centre of national knowledge for primary care physicians that will give advice and guidance regarding use of antibiotic in primary health care(Simonsen 2007).

2.4.6 Evaluation of surveillance system for early detection of outbreaks

Recently the threat of terrorism and high-profile disease has been more and more in media and therefore drawn more attention and question if societies have the necessary system to detect outbreaks and protect the public. Authorities has enhanced existing systems and developed new system to better detect outbreaks of communicable diseases. Therefore this system has had to be evaluated in order to determine the limitation and the effect of these systems. In this sense there have been developed guidelines to evaluate these systems.

The Centres for Disease Control and Prevention have developed a framework for evaluation of public health surveillance systems for early detection of outbreaks for (CDC) in US (CDC 2004). This is a cut down version of the framework, which contains several categories that need to be evaluated:

- System Description
- Outbreak Detection
- System Experience
- Summarized conclusions

System Description:
The system description is supposed to give an overall description of the system. The system stakeholders should be listed, in addition to all aspects of operation. These aspects should be described in detail given an overview of system wide processes, data sources, data pre-processing, statistical analysis and epidemiological analysis.

Outbreak Detection:
The outbreak detection part of the system has an overall goal to describe the detection timeline. How fast can we detect an outbreak, and how the different outbreak detections operate on tendencies guided by sensitivity and data quality?

System Experience:
The system experience should show the system usefulness, the flexibility, the acceptability, the portability, the stability and the cost.
The summarized conclusion should contain the recommendation for the use and improvement of the system for early outbreak detection.

Summarized Conclusion:
Even this framework needs improvement along with the detection systems for early outbreaks. It needs to be tested and tested over and over. This framework needs to be simplified and standardized in order to allow comparisons. All existing systems need to be tested in order to find out how well they perform in early warnings (Sosin and DeThomasis 2004).

2.5 Making decision

"Nothing gets done without someone first making a decision" (COIERA 2003)

Every time a patient consults the doctor, the doctor has to make some kind of decisions. This can be either by getting information from the patient or providing information to the patient. Other issues are what kind of information is required, how much information is needed. The whole day the doctor is making decisions. Sometimes a patient is treated or sometimes not. But what kind of information are the doctors using when making their decisions?

2.5.1 Introduction

A consultation often start with communication with patient before any

decisions is made. In this sense the doctor is starting searching for information that can contribute to the point when a decision has to be made. For both patients and doctors, time is money. Patients do not want to spend too much time with the doctor and the doctor wants to help the patient and then turn to the next patient in line. The amount of time available can influence the quality of the consultation. In England the doctor uses 8 minutes in average at each consultation if the patient was well known (Howie, Heaney et al. 1999). In Norway the time used for consultation is around 15-20 minutes on each patient (SH-Dir 2004). Since the doctors have very little time available for each patient it is essential that he makes the right decisions. Each doctor is trying to solve problems that the patient have. To do this the doctor needs information to start the process of problem solving.

In each consultation the primary care physician have three choices. First, he can start treating the patient without knowing exactly what is wrong or before he has the exact diagnosis. This means that he is treating the patient on suspicion. It might be that the patient are in an extremely bad condition and cannot lose time by waiting for results from the laboratory or from other tests.

Second, the doctor can start testing and wait with treatment until he knows the diagnosis of the patient.

The third decision the doctor can make are not to do anything and wait until the disease develops and the symptoms gets more specific. He may want to tell the patient that he cannot find anything wrong at all or he can say that the patient has a virus infection, and that the body and immune system will take care of the virus. In this case no prescription is necessary and the patient just has to wait until it goes away.

2.5.2 The ICPC-2ed

The official approved system for specification of symptom in Norway used by the primary care health is ICPC 2-ed (International Classification of Primary Care)(Trygdeetaten 2004) This classification system is the property of Wonca (World Organization of Family Doctors) (Wonca 2004) This classification framework is mainly developed for symptoms, and all the Norwegian doctors in primary health care use it. This classification system will also be used in the Symptom Based Disease Surveillance (SBDS) project. Below is the figure showing a part of paper version of ICPS

A Allment og uspesifisert

A01 Smerte generell/flere steder
A02 Frysninger
A03 Feber
A04 Slapphet/tretthet
A05 Sykdomsfølelse
A06 Besvimelse/synkope
A07 Bevisstløshet/koma
A08 Hevelse/oppfylning IKA
A09 Svetteproblemer
A10 Blødning IKA
A11 Brystsmerte IKA
A13 Engstelig for behandling
A16 Irritabelt/urolig spedbarn
A18 Bekymret/opptatt av utseende IKA
A20 Dødshjelp diskusjon/spørsmål om
A21 Økt risiko for ondartet svulst
A23 Risiko for sykdom IKA
A25 Engstelig for døden
A26 Engstelig for kreft IKA
A27 Engstelig for sykdom IKA
A28 Redusert funksjonsevne IKA
A29 Generelle symptomer/plager IKA
A70 Tuberkulose
A71 Meslinger
A72 Vannkopper
A73 Malaria
A74 Røde hunder
A75 Mononukleose
A76 Virussykdom med utslett IKA
A77 Virussykdom IKA
A78 Infeksjonssykdom IKA
A79 Ondartet svulst IKA
A80 Skade/traume IKA
A81 Multiple skader/traumer
A82 Følgetilstand skade/traume

D20 Munn/tunge/lepper symptomer/plager
D21 Svelgebesvær
D23 Forstørret lever
D24 Abdominal oppfylling/kul IKA
D25 Utspilt abdomen
D26 Engstelig for kreft fordøyelsesyst
D27 Engstelig for fordøyelsesykdom IKA
D28 Redusert funksjonsevne fordøy probl
D29 Fordøyelsesyst symptomer/plager IKA
D70 Tarminfeksjon
D71 Kusma
D72 Virushepatitt
D73 Gastroenteritt antatt infeksiøs
D74 Ondartet svulst magesekk
D75 Ondartet svulst tykktarm/endetarm
D76 Ondartet svulst bukspyttkjertel
D77 Ondartet svulst fordøyelsesyst IKA
D78 Godartet/uspes svulst fordøyelsessys
D79 Fremmedlegeme fordøyelsessystemet
D80 Skade fordøyelsessystemet IKA
D81 Medfødt feil fordøyelsesystem
D82 Tenner/tannkjøtt sykdom
D83 Munn/tunge/lepper sykdom
D84 Spiserørssykdom
D85 Sår i tolvfingertarm
D86 Magesår IKA
D87 Funksjonelle plager magesekk
D88 Appendisitt
D89 Lyskebrokk
D90 Mellomgulvsbrokk
D91 Abdominalt brokk IKA
D92 Divertikkelsykdom i tarm
D93 Irritabel tarm-syndrom
D94 Kronisk enteritt/ulcerøs kolitt
D95 Analfissur/perianal abscess
D96 Orme-/parasittsykdom
D97 Leversykdom IKA
D98 Galleveisbetennelse/gallesten
D99 Sykdom i fordøyelsessystemet IKA

Figure 9 The Norwegian version of ICPC. From www.kith.no

In Figure 9 we can see the Norwegian version of ICPC, which the physicians in Norway have to use. The blue coloured text is regarding symptoms and pains. These symptom base codes are from 1-29. The pink coloured text is to be used when there is a diagnosis. The code ranges from 70-99. There also is some black text, which is regarding processes, in range of 30-69.

The physicians should mainly use the pink text, if possible, from the doctor points of view after making a clinical evaluation. But if it's not possible to set a clear diagnosis, then the physician can use the symptom-based codes. Exceptionally, the physician can use the process part of the ICPC-code system.

2.5.3 Problem solving processes

The problem solving process will depend on the information that physician have collected. This will determinate what kind of processing that will be done? There are three kinds of reasoning processes. By studying the causes and effects of diseases we have developed medical knowledge.

Deductions are probably the most used process of diagnosis. We can

associate this with the fictional detective Sherlock Holmes. Holmes always said to Dr. Watson “That is pure logic”. By using logical terms deduction can be seen as this:

A > B
B > C
Conclusion:
A > C

Since this is pure logic, this can be proven. If a patient have fallen on ski and broken his ankle, then it is clear what the diagnosis will be in this case. The patient had broken his ankle and therefore the diagnosis will be broken ankle. In medical issues all of us can see that what the physician has learned in theory and practice is the medical knowledge. This knowledge is used when the physicians see the broken ankle and make a conclusion that the patient has a broken ankle(COIERA 2003).

Induction is a reasoning process that leads to a conclusion that cannot be proved to be correct. It only leads to the most likely result. As an example we can illustrate induction by using the influenza or flue disease. When a doctor sees patients all day long in his office and all of them have the same symptoms and the diagnoses are the same, the flue. By induction it is most likely that the next patient with the same symptoms that he sees also have the influenza or the flue. The doctor use induction by relating the doctors background experience with the symptoms that the current patient have (COIERA 2003).

Abduction is different from deduction and induction. With abduction an experienced physician asks a patient a set of initial question, the physicians will after hearing the answers, have six or seven hypotheses to work with. These hypotheses will serve as a basis for selecting additional questions. (Einstein 1978). When the doctor has finished the examination of the patient, he may have a list of possible diseases that fit the symptoms the patient have, and he may have reduced the list to as few as possible, and hopefully, just one diagnosis. However, if he has more than just one diagnosis to choose amongst, he may use tests to eliminate some diagnosis and find the correct, or the most likely diagnosis (COIERA 2003).

Physicians often use tests from the laboratories. These tests can be used to check whether a patient have a certain disease. A test can also be used to exclude certain diseases. This can tell the doctor how to use the different tests in order to find the right disease.

Sensitivity and specificity

Sensitivity of a test is defined as the probability of a positive result,

regarding the given condition under consideration present. (Edward H. Shortliffe 2001)

Specificity of a test is defined as the probability of a negative result, regarding the given condition under consideration present. (Edward H. Shortliffe 2001)

Overview of sensitivity and specificity

	Outbreaks	**Non outbreak**
True	True Positive	True Negative
False	False Negative	False Positive
	Sensitivity	**Specificity**

Table 2 Show the relationship between outbreak/non outbreak and false/true outbreaks.

Table 2 shows the how the specificity and sensitivity are related to outbreaks of diseases. The Physicians are depending on the system are giving the right information, if there is an outbreak or not.

2.5.4 Lab results

Every sample that is taken and examined by a laboratory is collected to investigate if there is something abnormal in the specimens. The doctor does not want to take any unnecessary samples because it cost money and time. The doctor probably is expecting something wrong when taking a sample, or he wanted to exclude something. The problem with analyzing a sample is that in some ways the results can be odd. In analyzing there is some uncertainly. Machines analyze most of the samples. These machines have some cut off values, and the result of positive and negative samples is spread in two distributed gauss-curves.

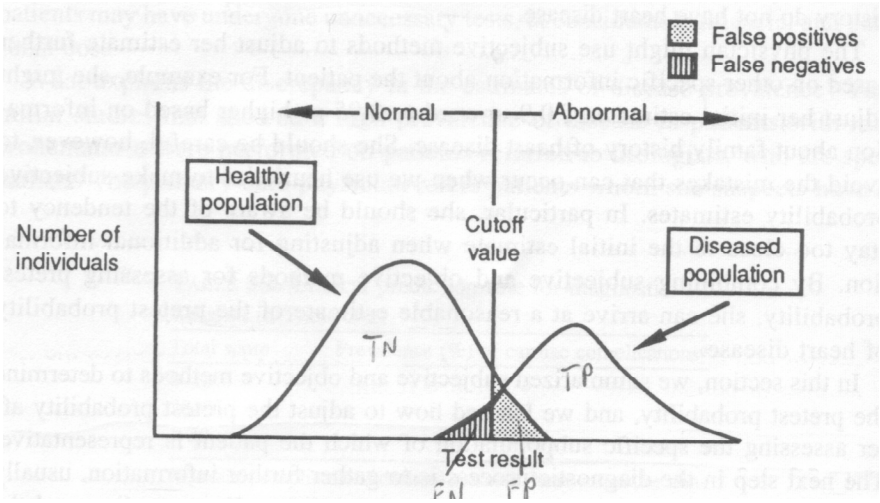


Figure 10 Distribution of healthy and not healthy persons (Shortliffe: Medical Informatics, p 88).

Figure 10 shows us two gauss-curves that divide the population in half. One curve is connected to the healthy population (TN=True Negative) and the other group is connected to the infected population (TP=True Positive). Near the cut-off value the curves cross each other. The section on the left of the cut-off-value, and connected to the infected population, the samples are classified as healthy but are in fact infected (FN= False Negatives). The area on the right of the cut-off value and is a part of the healty population, is classified as infected, but are in reality healthy (FP=False Positive), (Duglas K. Owens 2001).

When a physician is reading the results he needs to know about problems with analyzing the sample, and take that into consideration when he receives the results from the lab.

2.5.5 Usefulness of medical information

2.5.5.1 Introduction

The practitioners are been bombarded with information from many sources. Therefore many primary care physicians can find it hard to choose the right sources of information. The search for information is often needed when there is a special case or for remaining up to date with current knowledge within a medical field.

2.5.5.2 Information and sources

The information can be at help if it becomes knowledge and wisdom.

Information needs to be processed and taken into practice. The sources of information within medicine are many and the statistics are astonishing. The Medline databases contain 6 millions references from 4000 journals in 1994. This means that there are a lot of articles to read for the practitioners. The primary care practitioners often use sources as medical magazines, colleagues, audios, Internet, textbooks, newsletters, pharmaceutical representatives and specialists to stay up-to-date and obtaining answers to clinical questions (David C Slawson 1994).

2.5.5.3 Usefulness of medical information

Because there are many sources of information and knowledge, the primary care physicians are interested in spending as little time as possible on searching for an answer on a question in everyday practice. The information must be as relevant as possible and it also need to be correct. The patient can be injured or in the worst case die, if the information or knowledge is incorrect. In order to collect this information the physicians are willing to spend as little time as possible. We can use the equation from Slawson (David C Slawson 1994):

Usefulness of medical information = (relevance * validity) / work

The equation is essential with the concept of getting information in order to help the patient to have a long life, good functionality, have a satisfying life and a pain and symptom free life (David C Slawson 1994).

Relevance in this equation is related to the information that is needed or has to be collected to the specific disease or diagnosis in consultation. This will depend on the diagnosis or symptoms the patients in consultation have. According to the equation, the higher relevance of the information, the better for usefulness of medical information. In the end this will benefit the physician and the patient.

The validity of information is related to the knowledge gained to represent the truth. The best of test and clinical trial have used method to avoid errors and have proven valid conclusion in articles or publications. Often is the collection of validity information time consuming and may be difficult for physicians without training in epidemiology. Asking colleague the validity of published articles will not be any good solution for physicians to validate information. Therefore, if the validity of the information is high then this will benefit both physician and the patient.

The work in this equation is the work and time the physician has to use to find the information that is needed in this case. If there is a great workload

the physician's value of information get less. On the opposite side of the scale is less amount of work for good and valid information that have great relevance, then the usefulness of information are good for physicians.
Useful information is information that has good relevance, validity and requires as little work as possible to access. In some cases the parameter "work" can be high, but then the validity and relevance have to be exceptional good.

2.6 Visualization of medical information

2.6.1 Visualization at NIPH

2.6.1.1 Visualization of MSIS at web

Visualization of MSIS at Web is straightforward. The NIPH/MSIS report are based on tables that summarize the historical numbers of contagious diseases. There is no prediction about the future. The web page states that the numbers are based on daily updates.
There are three reports to choose among. This is the report:

- The number of single diseases. In this report the user can choose one disease and choose how to get the number displayed. The user can choose between the number distributed over county, sex, ages, places of contaminates and number of incidences this year compared with last 5 years on county level.
- Municipality and national statistics – Shows all diseases. This report has to variables:
    - Years (from this year and back)
    - Municipality overview or national overview
- Composing you own base on the other two reports. The user can choose disease, year, month, county, place of contaminates, sex, ages and ways of contaminates

Figure 11 shows a typical example of MSIS report on web.

Resultat

For enkelte sykdommer og tidlige årganger kan datakvaliteten variere.

Dato: 18.04.2007 (dd.mm.yyyy)
Sykdom: Aids

Tabellen viser antall tilfeller diagnostisert i tidsrommet 1.1 - 18.4 for årene 2002 til og med 2007

Antall tilfeller hittil i år sammenlignet med samme tidsperiode de siste 5 år, fordelt på fylke

Data sist oppdatert: 18.04.2007

Fylke	2002	2003	2004	2005	2006	2007
Østfold	1	2	-	-	1	-
Akershus	1	-	2	2	-	-
Oslo	5	3	8	7	7	1
Hedmark	-	1	-	-	-	-
Oppland	-	-	2	1	-	-
Buskerud	1	-	1	-	1	-

Figure 11 typical reports of MSIS. Test on top, a table below. The picture shows additional possibility to transfer result to spreadsheet. (www.msis.no)

2.6.1.2 Visualization of Utbrudd.no

NIPH provides a web portal for reporting of disease outbreaks. This is just a web page that anyone can get access to. Figure 12 shows the web pages that give the user the possibility to report an outbreak, follow an outbreak and view report.

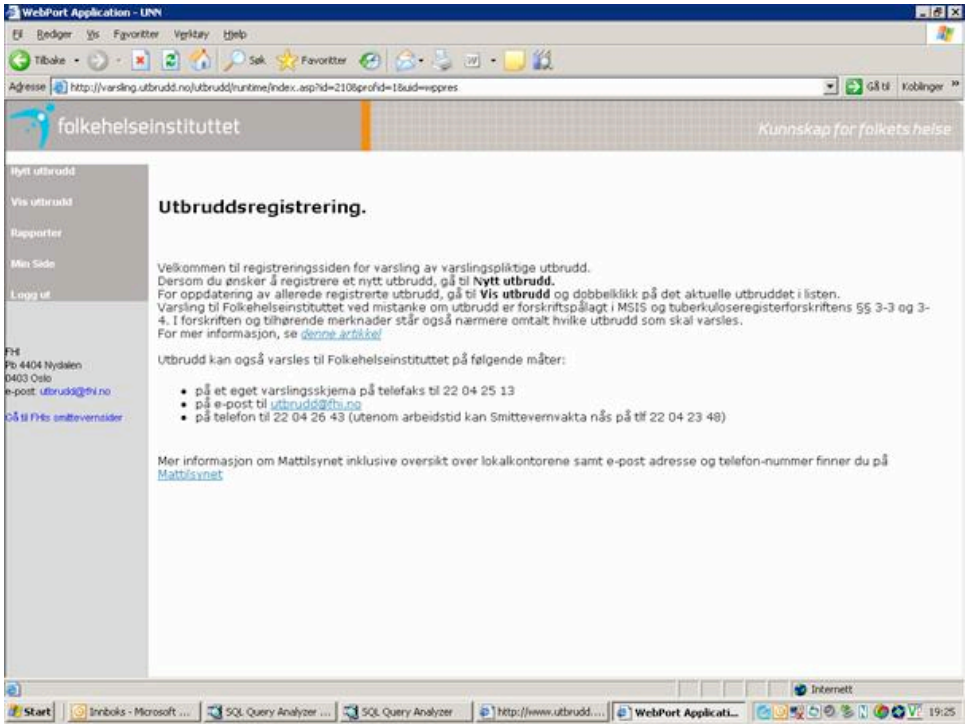


Figure 12 Show the welcome page of utbrudd.no after using username and password. The page describes the function of page and how to report an outbreak

2.6.1.3 Reporting an outbreak in utbrudd.no

In order to report an outbreak of a disease, the user has to fill out a form. This form is totally different from the one used in the paper version.

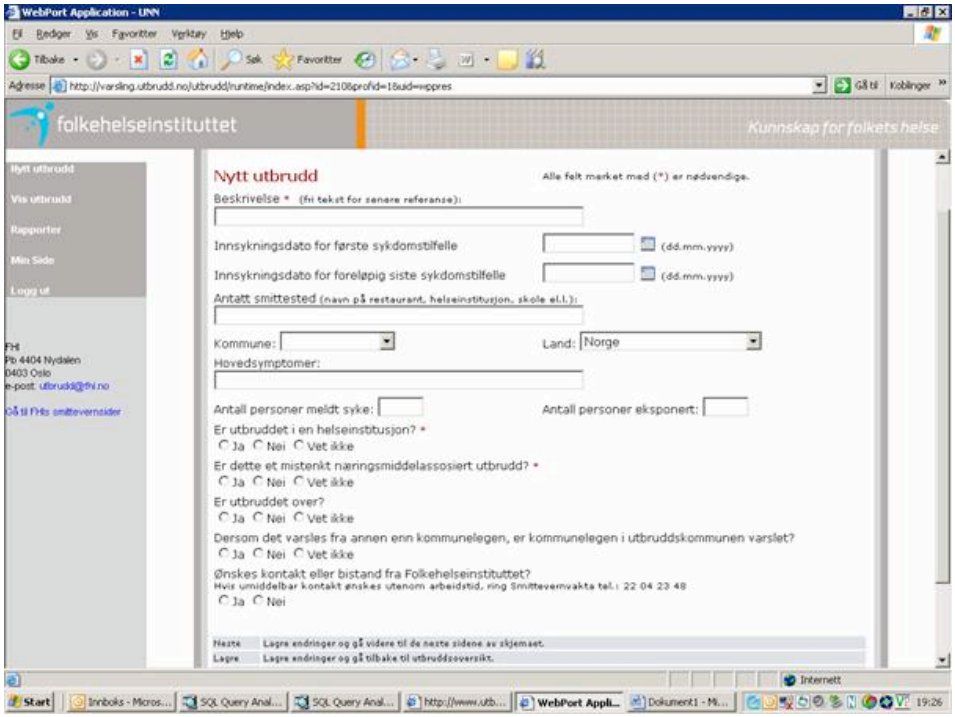


Figure 13 show the report form in utbrudd.no. It is only available in Norwegian.

Figure 13 shows what kind of information that is asked for. Some information is mandatory.

2.6.1.4 Evaluation report on utbrudd.no

The web page www.utbrudd.no was introduced in 2005 as part of the new and improved solution of reporting outbreaks in a national scale.
This solution was evaluated by a group of representatives from NIPH and Norwegian Food Safety Authority. The evaluation report was based on electronic question forms sent to all the registered users, (173) where 93 users have answered. Additional there were 83 users who answered by sending email and referred to the link for query investigation.
In the end of the survey results showed that 58% of the participants were satisfied with the new and improved solution. Approximately 10 % of the participants didn't feel the solution was any better or easier to use than the previous one. The group concluded that the user interface regarding reporting outbreak had to become easier (NIPH 2007).

2.6.2 Visualization of resistance

NORM today does not have any homepage that is presenting the data from the report to the public. But the NORM uses a system where several counties

in Europe cooperate to present statistics in an interactive database. The database is the EARSS (European Antimicrobial Resistance Surveillance System). On this web site the user can see antimicrobial resistance results from 31 countries. The easiest way to come to this web page is to use EARSS homepage, choose EARSS results and interactive database. Below are some examples of visualization of resistance.

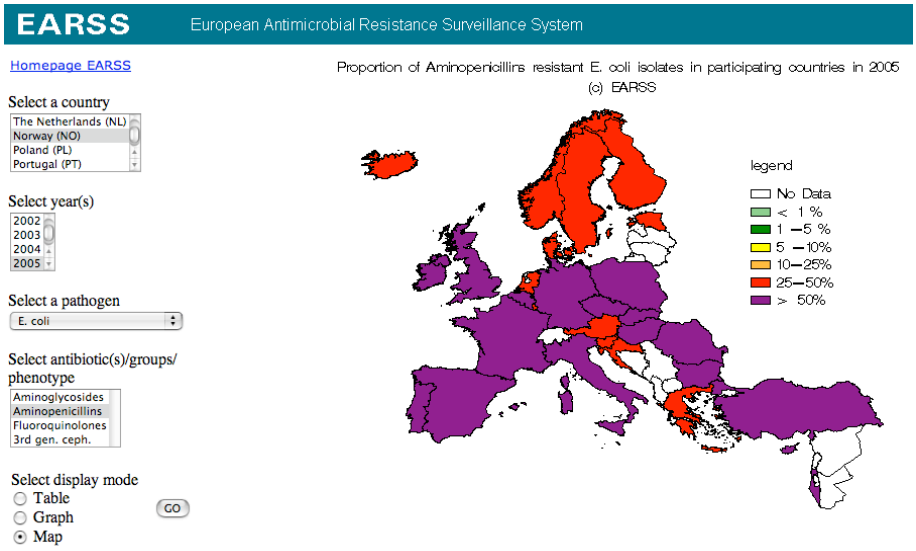


Figure 14 Show proportion of Aminopericillirs resitant E.coli in serveral european countries. It also show the choise the user have to do. From http://www.rivm.nl/earss/

Figure 14 shows how the output chosen in the webpage, can be shown. The resolution of the images is not possible to adjust.The primary care physicians will probably not use this kind of information since it is has obvious flaws in image quality and user friendlyness. Will the primary care physicians use this kind of information and access it. Figure 15 and Figure 16 shows other visualization form EARSS. Below is the same example as above. In the graph visualization we have to choose serveral antibiotic in order to get some good presentation.

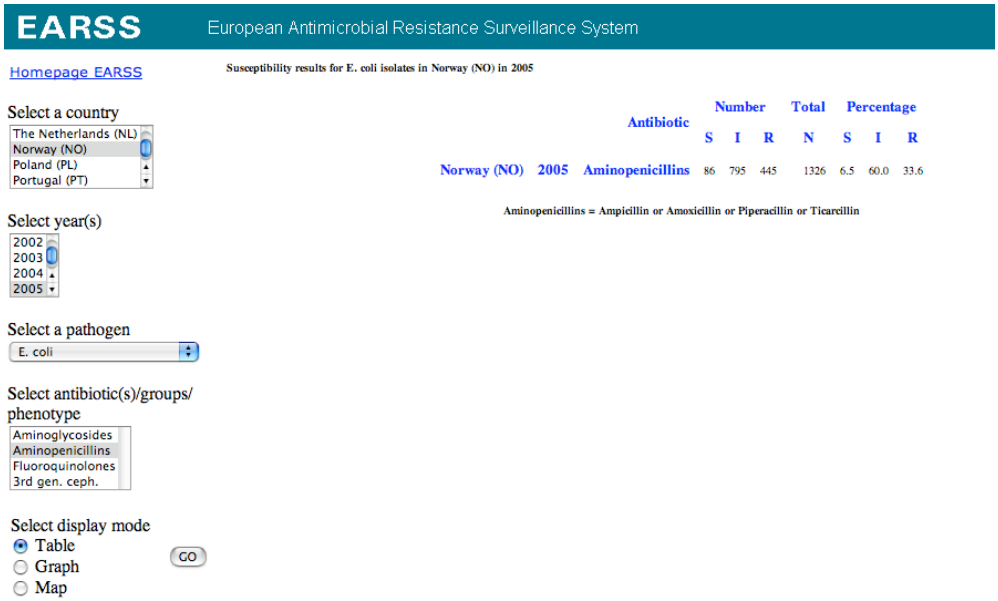


Figure 15 Table from EARSS that contain the same antibiotics as in the figure above. From http://www.rivm.nl/earss/

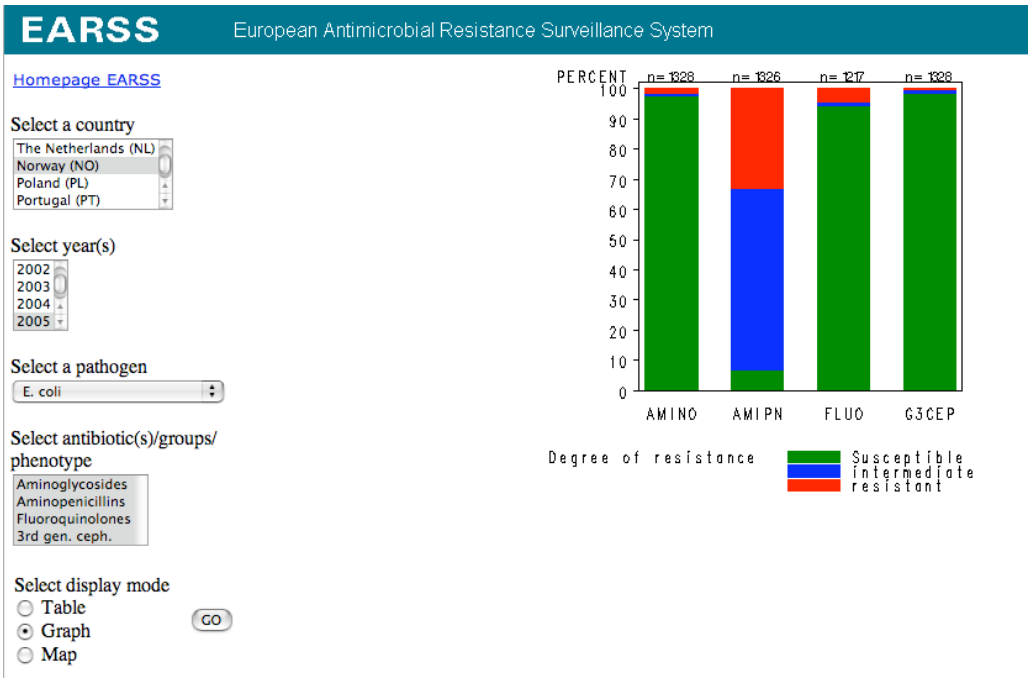


Figure 16 show the same as Figure 15, but we add some more antibiotics, from http://www.rivm.nl/earss/

2.6.3 Visualization from the Swedish Institute for Infection Disease Control (SIIDC)

The SIIDC is the Swedish version of the Norwegian NIPH. The institute use table, graphs and maps in their visualization of contagious diseases. This institute have an easy homepage where it is easy to find what you are looking for. By clicking the "Data & Statistics" it lead the user to the next level where they also have a web engine that you easily can navigate through. The page tells you how often the data is published and when you can expect new and updated data. The top part of the page is the same as the homepage so the user can easily navigate back to the starting point. On the left side the user can see an alphabetic overview of letters, to choose amongst. Below the alphabet, there is an option "*View of topic*". This makes it easy for the user to choose amongst different issues, such as antibiotic resistance, hospital diseases, bioterrorism, sexually transmitted infections and many more. By choosing either alphabetic letter or view of topic, the rest of page change after the user's choice. This will lead the user to the exact disease or other issue that can be chosen. By choosing one of these the user gets a new page where statistics are shown for the subject at hand. Figure 17 is the page shown when we choose "Hepatitis B".

County | Age | Sex | Cases per week | Trend | Country of infection | Map

Summary | 1997 | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007

County	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2(
Blekinge	18/11.84	15/9.88	20/13.22	35/23.22	36/23.94	28/18.65	38/25.32	28/18.62	22/14.59	19/12.54	9/
Dalarna	27/9.41	24/8.44	17/6.03	20/7.15	13/4.67	38/13.71	26/9.39	43/15.57	28/10.15	34/12.33	1(
Gotland	5/8.61	3/5.18	5/8.66	3/5.21	4/6.95	3/5.21	3/5.20	2/3.46	3/5.21	3/5.23	1/
Gävleborg	32/11.19	32/11.28	30/10.65	38/13.56	30/10.75	64/23.04	68/24.53	73/26.39	88/31.88	60/21.76	2:
Halland	41/15.13	37/13.59	44/16.10	42/15.30	47/17.02	34/12.24	44/15.70	31/10.92	31/10.84	24/8.30	6/
Jämtland	6/4.47	5/3.77	10/7.61	3/2.30	11/8.51	29/22.58	10/7.81	10/7.84	6/4.72	11/8.66	3/
Jönköping	43/13.08	41/12.49	35/10.67	36/10.98	53/16.15	38/11.58	34/10.35	63/19.13	26/7.87	52/15.68	1!
Kalmar	19/7.87	34/14.20	27/11.37	52/22.02	50/21.25	50/21.29	36/15.32	41/17.48	28/11.96	44/18.82	1!
Kronoberg	18/10.02	23/12.86	27/15.18	25/14.12	20/11.31	36/20.34	56/31.57	55/30.84	29/16.25	33/18.37	2(
Norrbotten	22/8.34	13/4.97	11/4.23	29/11.27	32/12.51	38/14.94	66/26.04	67/26.52	50/19.86	36/14.29	1:
Skåne	195/17.47	147/13.14	140/12.47	123/10.91	112/9.88	197/17.26	232/20.19	205/17.65	167/14.28	143/12.07	7(
Stockholm	575/32.78	458/25.82	451/25.14	412/22.71	444/24.24	431/23.36	495/26.67	431/23.01	348/18.41	345/17.98	1:
Södermanland	46/17.87	41/15.96	62/24.19	37/14.44	58/22.58	30/11.61	53/20.39	33/12.64	29/11.07	28/10.64	1(
Uppsala	63/21.72	49/16.83	54/18.48	46/15.67	34/11.50	54/18.13	41/13.67	34/11.23	31/10.18	22/6.87	1(
Värmland	12/4.26	23/8.23	33/11.88	40/14.49	48/17.47	60/21.91	71/25.94	47/17.18	40/14.63	21/7.67	1:
Västerbotten	32/12.32	21/8.11	31/12.04	18/7.02	36/14.09	25/9.79	74/28.93	42/16.35	27/10.47	39/15.14	1!
Västernorrland	48/18.77	32/12.63	34/13.55	39/15.70	40/16.24	53/21.64	56/22.91	54/22.11	59/24.20	65/26.64	3:
Västmanland	36/13.87	48/18.58	32/12.43	29/11.28	27/10.48	44/17.01	40/15.40	52/19.92	36/13.77	33/13.28	1!
Västra Götaland	319/21.47	199/13.38	205/13.77	597/40.01	320/21.36	294/19.53	262/17.33	270/17.74	231/15.11	196/12.74	1(
Örebro	50/18.13	28/10.18	41/14.94	28/10.22	45/16.45	58/21.21	114/41.63	91/33.22	67/24.44	66/23.99	2:
Östergötland	61/14.69	43/10.39	44/10.67	40/9.72	31/7.52	116/28.08	98/23.65	66/15.86	60/14.41	42/10.04	1:
Total	1668/18.84	1316/14.86	1353/15.26	1692/19.06	1491/16.75	1720/19.26	1917/21.39	1738/19.28	1406/15.53	1316/14.44	5:

Figure 17 Hepatitis from Swedish Institute for Infection Disease Control.

Figure 17 shows different numbers. The overview of this table in the figure is not easy to use because it contains too many numbers. The red numbers are "Total number of cases". Blue numbers are "Number of cases pr 100 000

pop. And year".
In addition to tables there are different choices at the top of table. The choice County, Age, Sex and County of infection are other tables based on the same aggregated numbers. The choice "Cases per week" and "Trend" will generate charts. Choosing the option map will generate maps. In Figure 18 we can see the Trend preview. This figure will help the viewer since it has the trend line included.

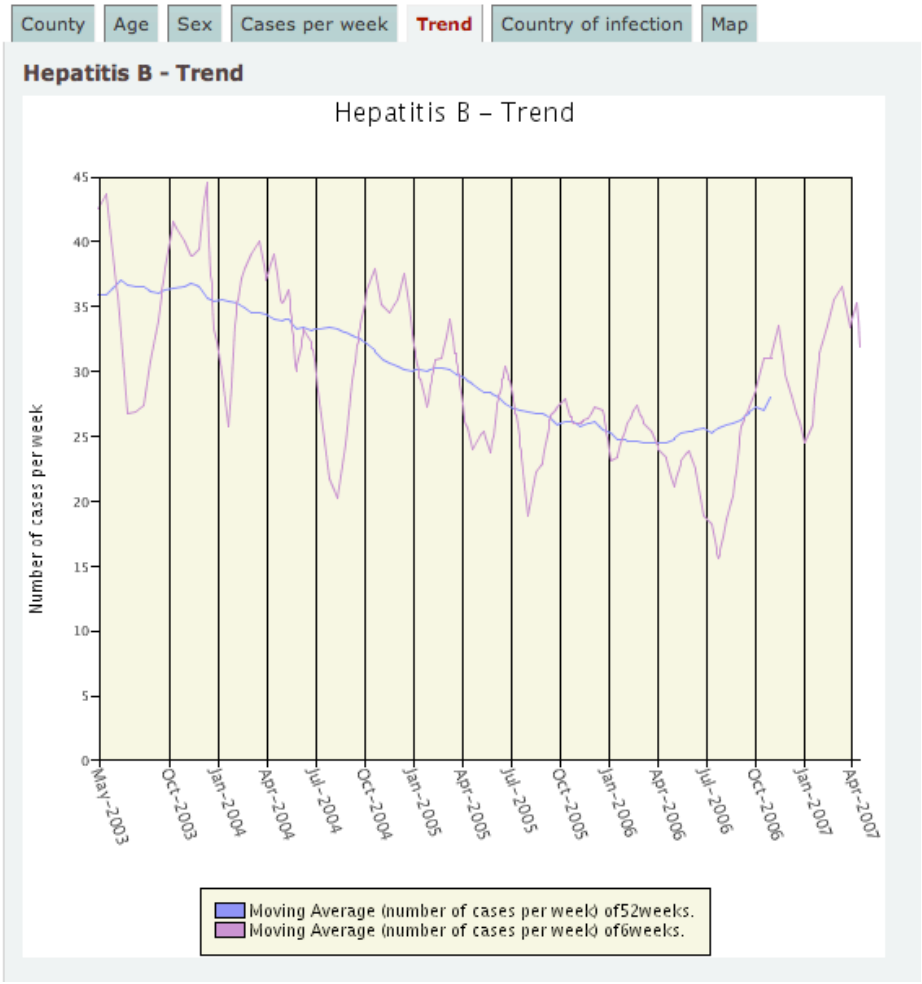


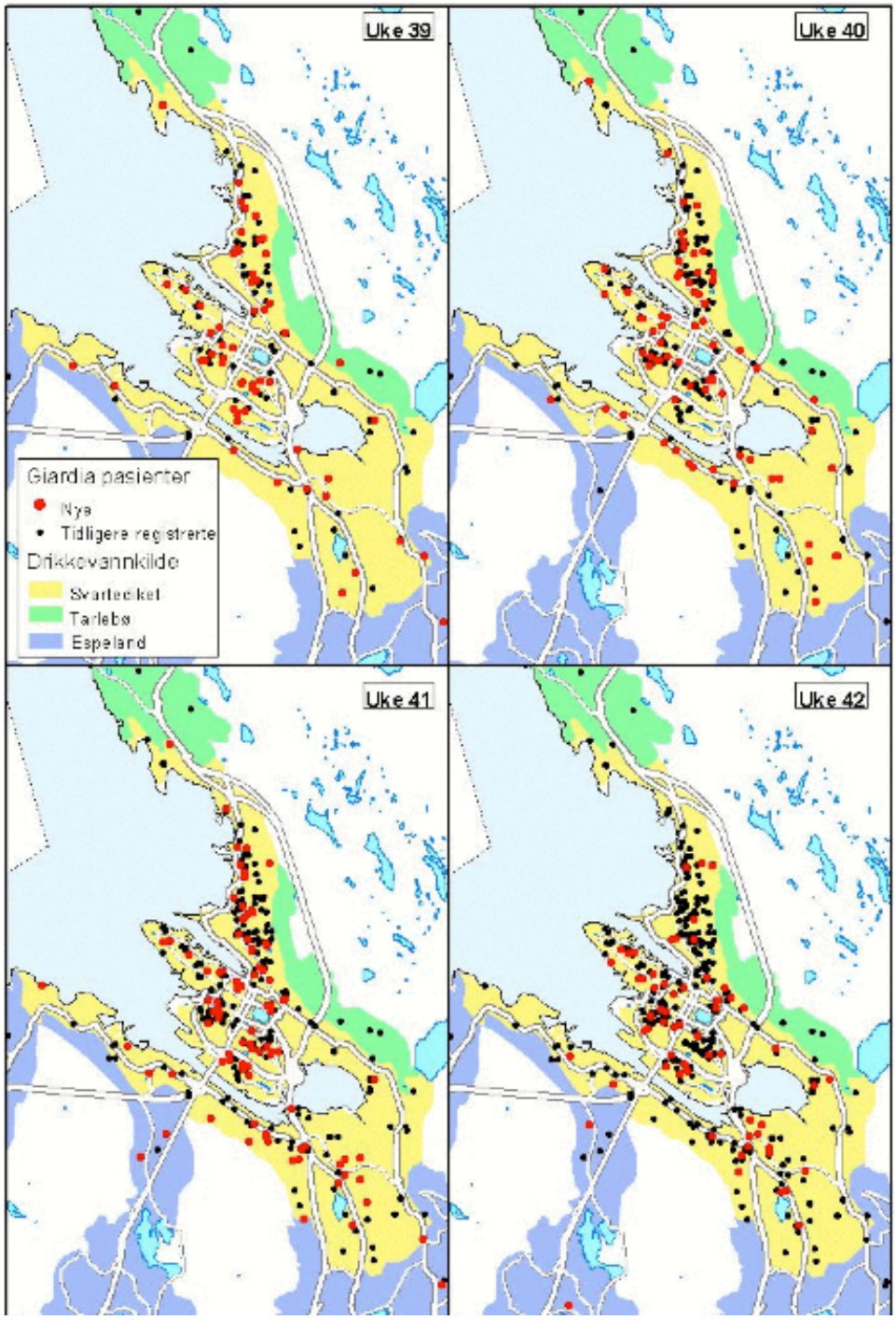
Figure 18 Trends of Hepatitis Mai-2003 - Apr-2007 from the Swedish institute for Infection Disease Control. Ref. www.smittskyddsinstitutet.se

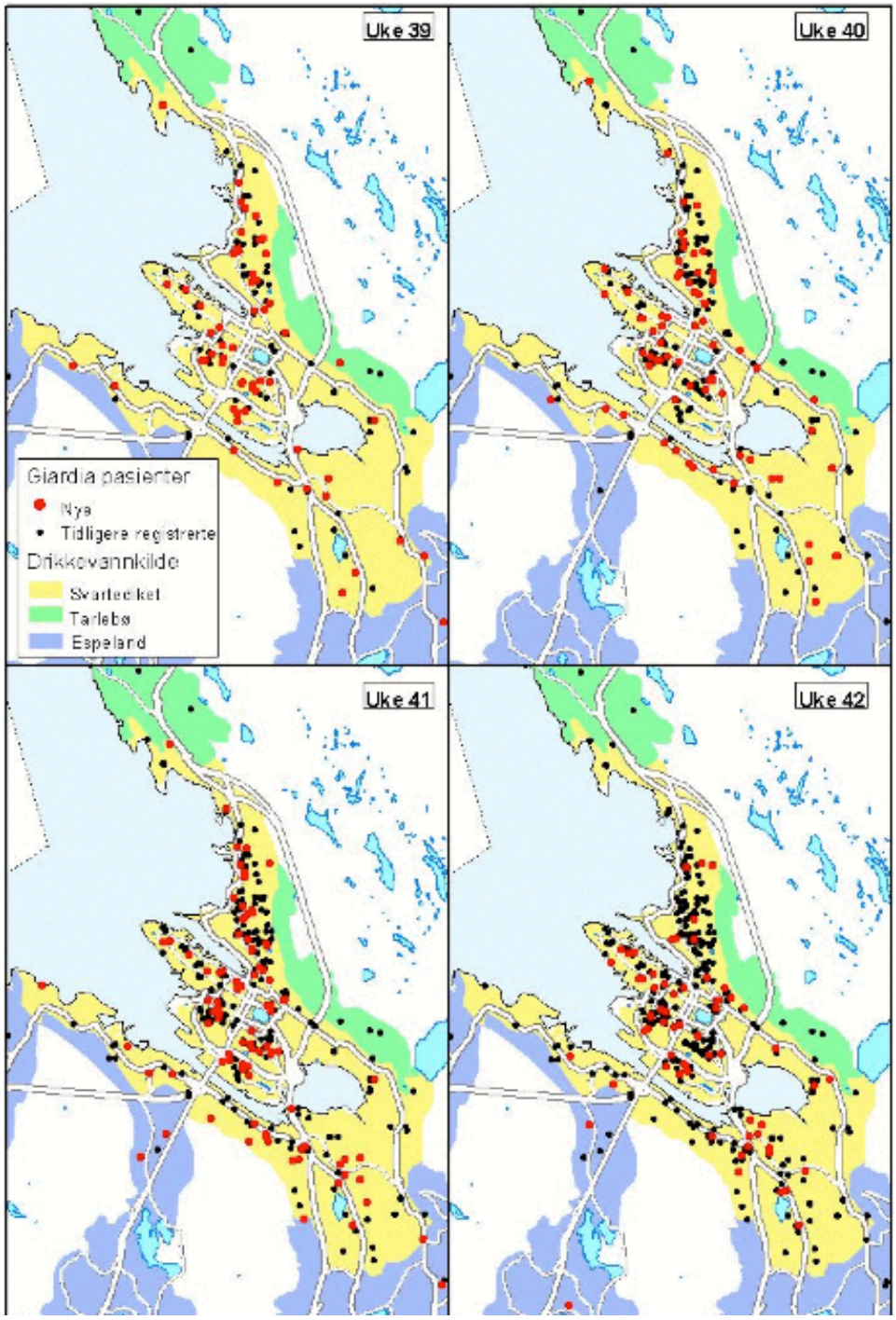
But in order to get to these web pages there is a lot of user interactions needed. This will probably not be used every day by the primary care physicians. Also the numbers that are displayed are some weeks old. But they can be interesting for research (Control 2007).

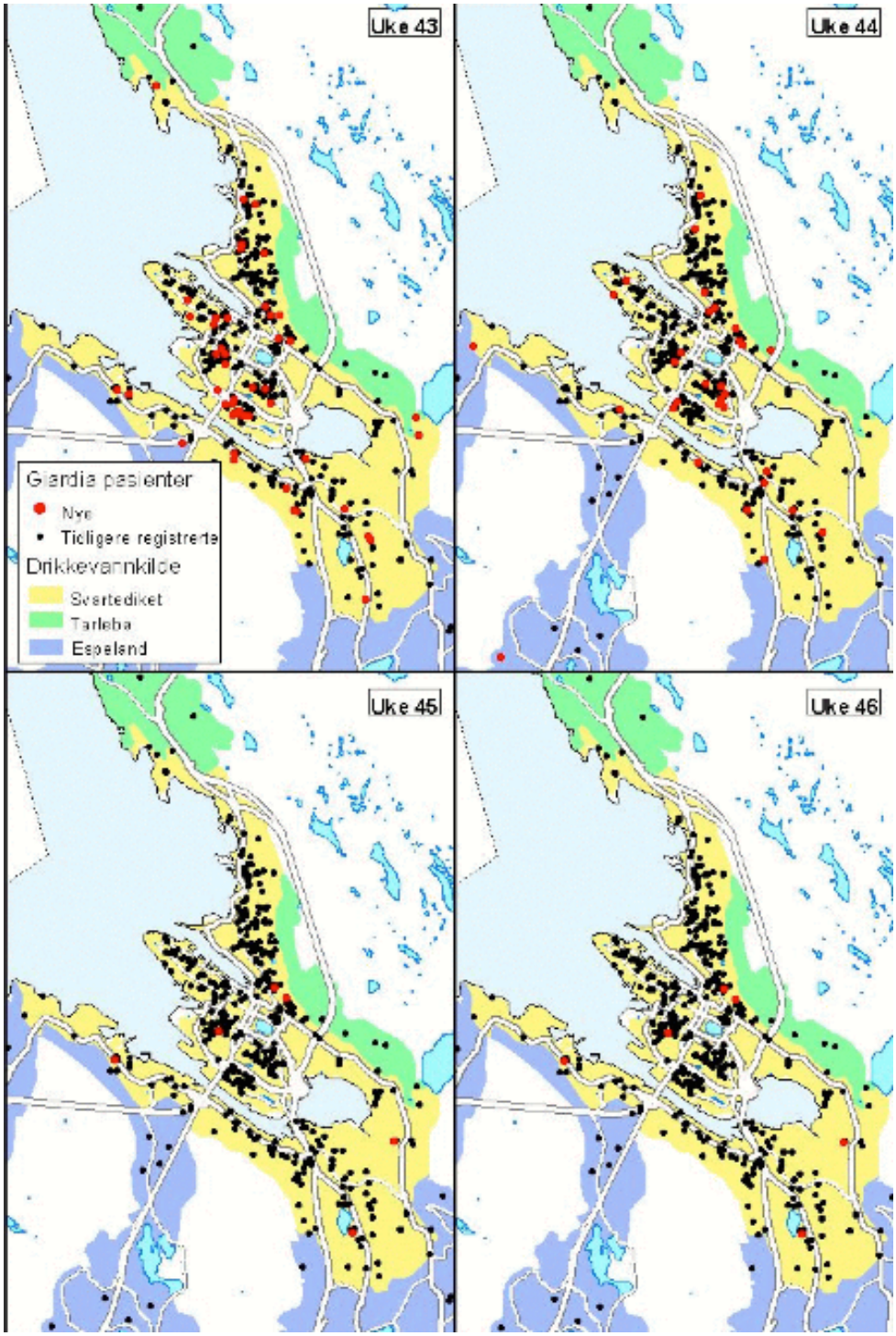
2.6.3.1 Example on visualization on outbreak in Norway

During 2006 there was an outbreak caused by contaminated food. This happened when an aggressive type of "E-coli" infected 18 people. The first cases of patients were discovered 20th of February 2006. The source of this contamination was not discovered until 22nd of March. 16 of the infected were children. Ten of the infected got "HUS – (haemolytic uremeisk syndrome). One of these cases had an tragic outcome, as one of the children died of kidney failure caused by the infection (Brustad 2006) (NIPH 2006).

Figure 19 shows the development of the disease in Bergen during the outbreak. Duration time between each picture is one week. During 16 weeks from week 35 through 46, black spots were incidences registered the week before and red spots were registered the actual week.


Uke 39
Uke 40
Uke 41
Uke 42
Giardia pasienter
Nye
Tidligere registrerte
Drikkevannkilde
Svartediket
Tarlebø
Espeland


Uke 39
Uke 40
Uke 41
Uke 42
Giardia pasienter
Nye
Tidligere registrerte
Drikkevannkilde
Svartediket
Tarlebø
Espeland


Uke 43
Uke 44
Uke 45
Uke 46
Giardia pasienter
Nye
Tidligere registrerte
Drikkevannkilde
Svartediket
Tarleba
Espeland

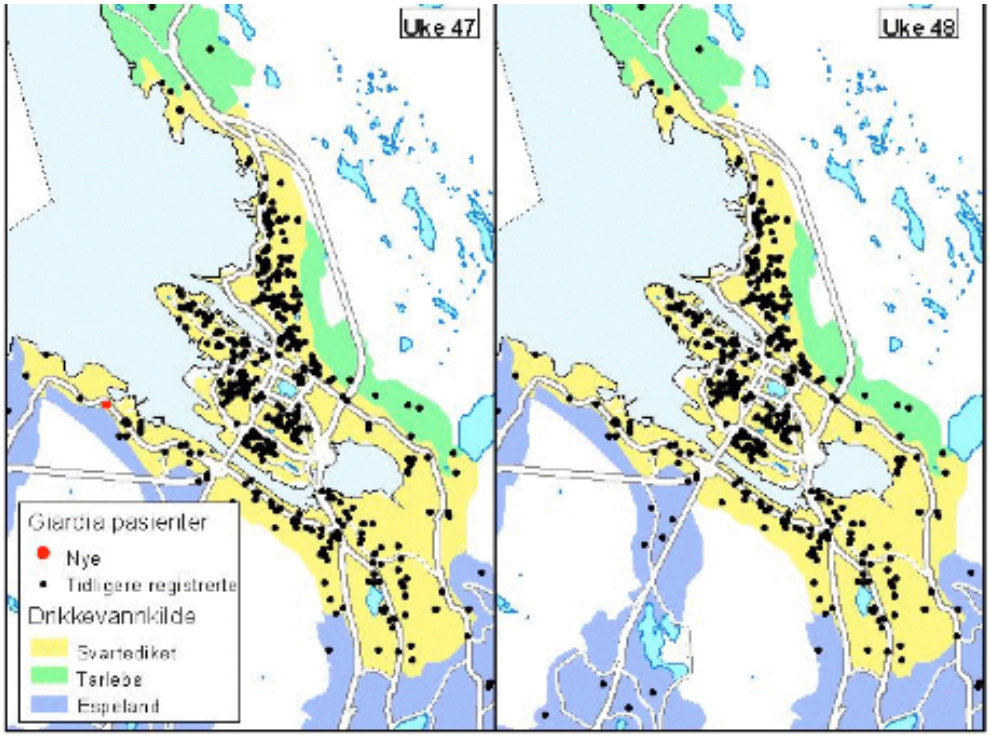


Figure 19 Black spots show registered incidences, Red Spots show new incidenses for 14 weeks in Bergen of the Garida epidemic (from (Biologer 2005)

2.7 Technology Acceptance Model

This is an abbreviated overview of the theory of TAM (technology acceptance model). Fred Davis conceived the original model in 1986.

The TAM was derived from the theory of TRA (Theory of Reasoned Action) and the TAM model intention was to be used in information technology research, but have been widely accepted and also been proved to reasonably accurate predictive by user that have intention to use information technology and system usage (Associate Professor William Money 2004).

TAM provides an explanation of user acceptance in general and is capable of explaining the user behaviour across a range of end-user computer technologies.

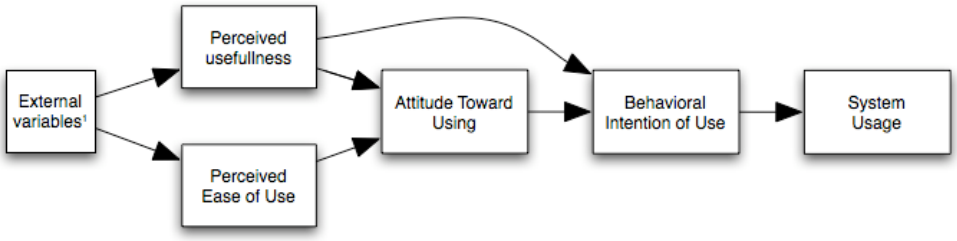


Figure 20 Technology Acceptance Model (Davis)

Figure 20 shows how the perceived usefulness and perceived ease of use affects the final use of an information system.
TAM removes or left out several parameters as adoption of invention, cost-benefit paradigm, expectancy theory and self-efficiency theory.

Later on the "Research Model of TAM" has been developed. This model is supposed to be used for research in relationship among TAM. See Figure 21.

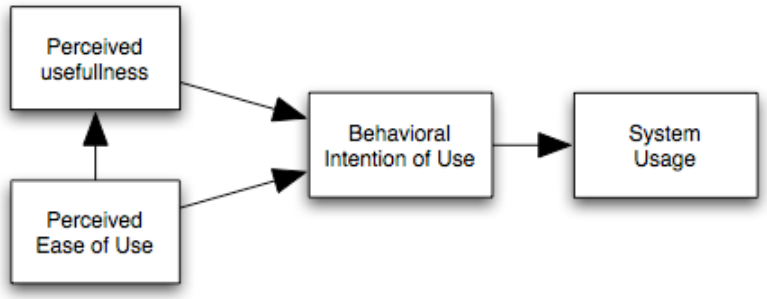


Figure 21 Research Model of TAM

This research model is very similar to the original TAM model. (Figure 20) But in this research model the "Attitude Towards Using" is deleted. The removal of this is done accordingly with Davis, et al (1989), which was best as a partial mediator of the effect of perceived usefulness that added little causal explanatory power. Also the external variable is not included because in the research model there is no intention to investigate these (Associate Professor William Money 2004).

Several research results have confirmed the usefulness of TAM. These have been done with various extension and revisions, in order to be able to predict the user information technology acceptance (Associate Professor William Money 2004).

2.8 Summary

Today there are mainly three different infection disease control systems.

- Reporting system from primary care physicians, hospitals and laboratories.
- Sentinel surveillance systems
- Syndomic surveillance systems

Both the Norwegian Institute of Public Health (NIPH) and Swedish Institute of Infection Disease Control (SIIDC) are both providing historical numbers of contagious diseases on Internet. These systems are basing their numbers from primary health care system, hospital and laboratories reporting.

The Norwegian sentinel systems use 200 medical offices where some is reporting on specific diseases while other are reporting on sample that has been investigated. Example of a syndromic surveillance system is the Real-Time Outbreak Disease Surveillance (RODS) system that are basing their numbers from hospital admittances, pharmacy, emergency unit, biosensors in additional to non-clinical indicators.

Most of the information about contagious diseases are available on the Internet and are visualized in different forms, but the physicians need to go out and seek for the specific information that is relevant. The physicians are trying to seek information that is most relevant to the need they have and use as little as time as possible on this search. Currently, this requires a lot of clicks thru different web pages.

When the physicians get the information he will use his knowledge and information from patient to make decisions in order to help the patient. When the physicians make decisions there are normally three types of reasoning processes involved:

- Induction
- Deduction
- Abduction

The physicians will use on or more of these techniques during the consultation.

Chapter 3

3 Methods and Approach

3.1 Introduction

During the time available for this thesis, we have been sweeping several types of methods. The methods we have been using in different levels are:

- System development methods
- Research methods
- Projects metods

When this thesis was given, we draw a plan of what kind of work we had to do. Also we tried to estimate the time for each part of the work, but when we look back many thing took much more time than we expected.

The system developing methods was used when we developed the visualization. It was also used during the interview, when we tried to find out the requirement for the new system of symptom based surveillance.

The research methods we used were as results of the visualization. After we decided how to work with the visualization this lead me to interviewing the physicians. Nearly all physicians we asked wanted to be interviewed. But it was hard to find free space in their time schedules. The main problem was to manage to do the interviews before it become too late. If more time had been available, we would have liked to do some more interviews. Due to lack of time the number of interview subject are just five.

3.2 System Design

The Symptom Based Disease Surveillance (SBDS) project have just been initiated and started. The projects have to find out what kinds of information sources physicians have and what kind of information the primary care health physicians need. To do this they have to collect information from users and other involved personnel. This can be done in many ways. The collected data of information will reveal which way the physicians work, how the workflow is and how they work with the patient.

Chapter 3 - Methods and approach

The main issue for this thesis is first to collect information on how the physicians are getting information about epidemiology and contagious disease outbreaks. This will tell us whether they use the MSIS statistics from the Norwegian Institute of Public Health if the physicians collect information about epidemiology and contagious disease from other sources?

The second issue is how often the physicians use this information about epidemiology and contagious diseases. It is also important to know whether the information is presented in a way that make it easy for the physicians to use it in their work with the patients. How often does he collect this information and what does he use it for?

The third issue we wanted to explore is whether there are other methods the information can be given to the physician? What kind of visualization is the best way to present this information?

In computer sciences there are several methods for developing systems. In our case we need to reveal the processes used by the physician and what information that is currently available and what information that is needed.

Some of the main direction of these methods are waterfall-methods, eXtreme Programming (XP), top-down programming, structured programming, Structured Systems Analysis and Design Methodology (SSADM), Information Engineering, Jackson Structured Programming, Dynamic System Development Method, Object-Oriented Programming, Rational Unified Process (RUP), Enterprise Unified Process (EUP), Agile Unified process and probably more.

We have to investigate the use of statistical reports and data from MSIS to discover if there is a gap between the information that is available for primary care physicians and the information that the physicians really need.

Normally the developing of any system goes thru different phases. The phases can be:

- Project identification
- Project Initiation and planning
- Analysis
- Design
- Modelling
- Programming
- Implementation
- Testing

This thesis is just involves a few of these phases. We did some analysis

when we were trying to find out what kind of information that was relevant for physicians related to contagious diseases. We also used the design phase when we were constructing the visualizations that was presented to the physicians. During the analysis phase we extracted requirements from what the physicians said during the interviews we had.

3.2.1 The focus area of System development

System development can embrace all from small tiny project that costs very little money to huge projects that can cost millions to develop. An example of a big project is Microsoft Corporations latest operational system Vista that has been under development for several years and has cost Microsoft millions of dollars to develop before it was released.

There are also many methods for system developing. We will in this thesis use the System Development Life Cycle (SDLC)(Jeffrey A. Hoffer 2002) as methods for software development. The SDLS is divided into six fazes. The phase is: Project identification and Selection, Project initiating and Planning, Analysis, Design, implementation and maintained.

This thesis will focus on second and thirst phase of SDLC developing. The first step is to identify the problems that the project have set focus on. The first we will focus on is if there is a problem with epidemiology in primary health care. Is there a need for a system that can increase the resolution and frequencies of report of an epidemiological data and contagious disease outbreak? Do the primary care physicians need this? In order to find out this we have to go to the physicians and ask them and other potential user of a system like SBDS.

3.3 Interview theory

3.3.1 Introduction

We have used interviews in order to get information about how the physicians get information regarding contagious diseases, whom they inform if they find patient with contagious diseases and what is the advantages and disadvantages with the reporting system today. We have also tried to find requirements for a new system of contagious diseases where physicians share information. The information is also used to specify the requirement regarding the visualization of the information in the future system. There are several interview techniques available which can be divide into structured and semi structured interviews.

3.3.2 Semi structured interviews

The goal with the interview is to collect information, rather than measure any differences in variables. The person that is interviewed is considered as an informant. The number of informants that is necessary is depending on the purpose of the interview.

In teaching books step by step a survey-investigations are often done according to usual practice. But with a semi structured interview there is more flexibility. The arrangement of the interview can either be done stiff or flexible.

With a stiff arrangement, the interviewer is developing the subject. Each subject is dividing into smaller subjects; in order get more precise answers. The part-subjects are assembled as an interview guide. Most of the survey-investigation interviews have closed questions. The semi structured interviews have most of the time used open questions, which the informant can choose either he wants to answer or not. Analysis starts after the interview.

The flexible arrangement is more open. It often starts with problem, but the interview can go in other direction than the initial problem. As a result this can lead to changes in the arrangement for the next interviews, the interview guide, the problem, other kind of people that need to be interviewed. Analysis often starts during the interviews. Since the question is open, the answers are not necessarily comparable with each other.

3.3.3 Interview guide

The interview guide is supposed to help the interviewer and ensure that all topics are covered. The guide can provide the security that a beginner need. The guide should be a one page containing open formed question or questions in the form that is wished. The question or theme can be taken in the order that becomes natural during the interview. In some cases it can be good for the research to ask for background information about the informer as education, age or occupation. The background information can be done in a structured way. Some choose to ask for background information in the beginning of an interview as a start.

3.3.4 The interview process

It is good conduct for the interviewer to tank the informant for spending time to the purpose. The interview should start with pointing out the purpose of the interview and ensure the informant that the information will be kept confidential and use in a way that the source of the information cannot be traced. By doing this the interviewer ensures mutual trust.

Often the questions are sorted as grand tours around each of them, and the interviewer will add additional question to get all the information from the informant that is necessary.
It is urgent that the interviewer do not use leading question, but ask in a neutral way. This will give the informant more room to improvise.
The interviewer should try to read the body languages and make notes with this in mind. Observation as sincerity, cooperation, and the location is important to have in mind that can affect the interview.

3.3.5 Registration of data

During an interview of this type it is normal to use audio or video recording and to create additional notes. Even if the interviewer uses a strict way of interview, it is wise to make notes and refer to number on question and make notes of keywords. After the interview there have to be written a report that based on the notes and memories of the interview. Some informants do not want to have the conversation recorded. Then the notes are essential. With no record it is harder to listen and write and some things that are said can be missed. In order to make a good report after the interview, it is essential that the report be written directly afterwards.

The best way to get the answer written is by using audio or video recording. The informant must be asked and approved in advanced to use recording during interview (Ringdal 2001). The best is to give the informant a written agreement on how the record will be used. The written agreement will be one copy to each. When the interview is finish, the interviews have to be written in text. Then the interview will become available for analysis.

3.3.6 Analysis of the interview

Analysing of the interviews have been done traditionally manual, but lately software program have been used to analyse this type of interview also. The simplest form of techniques these program uses is to search for words in text

files.
Mainly there are two type of program for analysing of these kinds of interviews. One is the program NUD*IST (www.qsrinternatinal.com). NUD*IST stand for Non-numerical-**U**nstructured **D**ata **I**ndexing **S**earching and **T**heorizing, which is a software to support qualitative research projects. Once the interview is written, the program can search for keyword or string, it can also code inside the program to choose from lines, sentences or paragraphs. The data is analyzed. The program is mainly of help with organizing data, processing data and presenting data.

A different program is the Texpack from ZUMA (Centre for Survey Research and Methodology) in German (www.gesis.org/en/software/textpack/index.htm). This program is mainly used for study languages when using simple word or combination of words.

3.4 Methods

3.4.1 Start-up of SBDS

The SBDS project has just started and the first project meetings were at 8 of mars 2007. All personnel that will have a part in the project were identified up to this date. The stakeholders, project management, the designers, the engineers and other participants were at this meeting.

3.4.2 Qualitative or quantitative method

There are two main groups of research methods, quantitative and qualitative methods. We apply qualitative methods. We will use interviews of primary care physicians that will help to establish their information needs. Qualitative research methods are used for search in depths. By doing this, we hope to find out why the primary care physicians can use the patterns of contagious disease visualization. It may also be the case that they cannot use the pattern at all. We also like to find out which pattern can be use in different situations.

The quantitative research method is aiming at numbers of trail and extensiveness of certain elements. This method could have been used if the electronically system in the SBDS project had the application in use by primary care practitioners. Then we could have to let the computers tells how much the practitioners used the patterns during the day. It would also be possible to, tell in which situations the systems were in use. Then when the

data collection phase is finish, we could use statistics to help us analysis the data and check the results against our hypothesis

3.5 Interviewing – How we did it

3.5.1 Introduction

The interview process was the most challenging part of the thesis work and the process that took most resources in terms of time and work. All subject for the interviews had to be chosen and contacted. They were asked to participate in the project when they were informed and asked to participate in the interviews.
Before the interview process started, the question was formulated and discussed. The discussion was focused on finding the right question that could meet the purpose of the interview. The time used for this went over weeks.
Five physicians were interviewed and contributed to this thesis with their answers.

3.5.2 The way question was made

The question made for the survey of the informants was focused on how the primary physicians collect information from different sources when and if there was a contagious disease outbreak. The informants were not supposed to know the question before we performed the interview. The only information the informants got was information about the project, the projects purpose and goals. It was also said that the project planned a software licensed that supported open source and free software distribution. The informants were asked if they were interested in participating future in the project after the interview.
In addition the thesis focus on how the project should be present for the user and how to present the information.

3.5.3 Recruiting physicians

All the physicians were recruited by direct contact. The contact was done by email or phone. Some of the physicians were more or less chosen by us. Others were more natural to ask, because of the responsibility they have. This was the case with the physician that is responsible for infectious disease prevention in the municipality of Tromsø. Initially the informant was chosen

from Tromsø, but there was also one physician from Finnsnes. One of the reasons for working together with Monika Alise Johansen was to avoid two different interviews related to the same subject.

3.5.4 Interviewing physicians

The plan was to use audio recording when interviewing the object. This happened, but in one incidence there was not taken any recording of the interview. Before any of the interviews, the physicians were asked whether they had objections to using recording equipment during the interview. All subjects were asked to sign an informed agreement on how the information of the interview was used and how the information was stored.
The interview was divided into sections giving the agenda below.

- Signing the informed agreement of the interview
- Presenting the project
- The interview part
- Presenting and discussing the visualization prototype

All interview objects were told that the interview was suppose to take between 45-60 minutes. After the first interview the question had to be reorganized and thoroughly prepared again since the time limit was broken. This resulted in some changes to the questions asked.

3.5.5 Report of the interview

The report after the interview is written in text, organized based on the question. The question was written in the report. Below the questions all answers were noted. Sometimes the interview subject answered before we had asked questions, then the answer was noted below the most significant question.

3.5.6 Question we used to interview the physicians

We tried to use question that describe why they used or did not use the specific information

The main question we asked

- How do you get information, and how do you find information about contagious diseases today?
- How do you use the current system today to detect outbreaks and

diagnose contagious disease?
- How do you use the ICPC-codes regarding symptoms and diagnosis for contagious diseases?
- If there is developed a symptom based surveillance system for contagious diseases where information is shared between primary care physicians, what is necessary to feel that the system is safe and how do you want to use it?

Some had other sub-question to ensure that we got answer on every issue that we wanted to be address. The complete list of questions that we used is listed in Norwegian in appendix F.

3.6 Summary

During the work with this thesis we used different methods. Some of the methods were more used than others. The most used methods were the qualitative information collection and design methods were all presentation of visualization was done.

Chapter 4

4 Requirement

Requirement will describe the necessary requirements that have been elicited out from the interviews with the primary care physicians.

4.1 Introduction

The primary goal of Symptom Based Disease System (SBDS) is to deploy a prototype system within one year and a half. In order to be able to do this, the project needs to get input and requirements from the end users, in this case the primary care physicians. We have encouraged the informants to describe with their own words the need for such a system. The issues we wanted the informant to give us information on was

- How information should be presented to the user
- How often the information should be presented the user
- Which part of the information was most useful for the physicians?
- Make a list of diseases that could be used in during a test period.
- We ask them about system security and how they feel about, extracting information from their electronic health record system.
- We tried to find some limitation regarding the configuration of system. How could this be done?

The interview was supposed to take 45-60 minutes, but the duration of most interviews was between 90 and 120 minutes.

The presentation of visualization was made simple in order not to fill it with too many details. The main thought was to keep it simple and clean and let the primary care physicians come up with their ideas. This will hopefully make the physician feel that they are allowed to contribute and establish ownership to the system and its properties.

4.2 The interaction with the system

4.2.1 “Pop up”

The most obvious thing that strikes us was that the informant wanted the information to be presented TO them, without any interaction with other programs.

The physicians stated that they ideally wanted the information to arrive in some sort of “pop up” on the computer. Either as a service running and listening for new information or as a small application that is started by a simple click, showing the latest updates from the source.
The most natural place to put this”pop up” was in their own Electronic Health Record (EHR)-system.

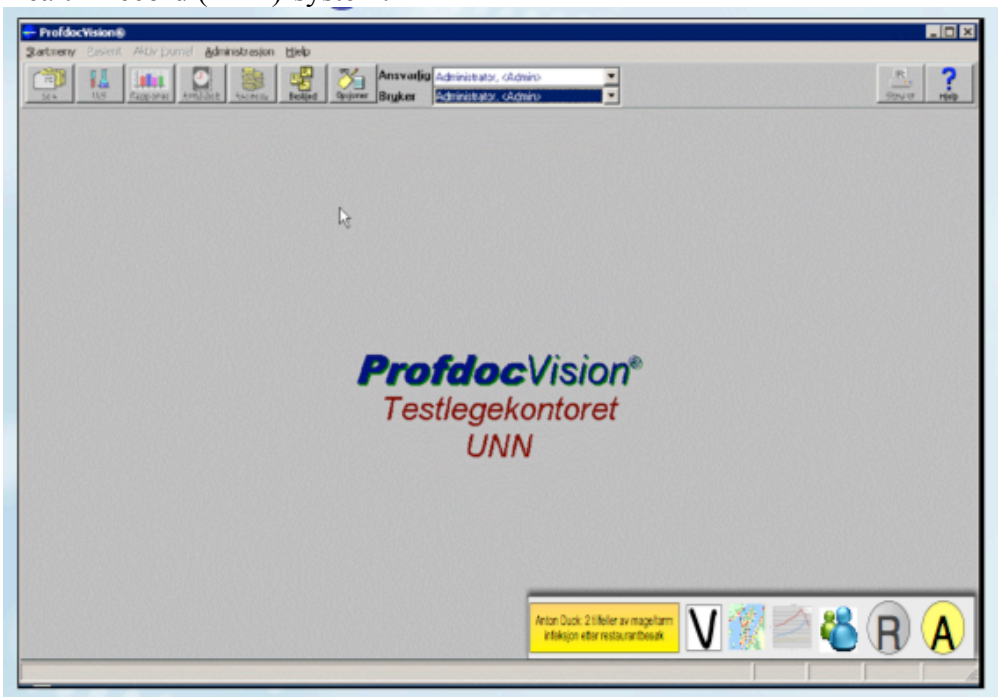


Figure 22 showing the "Pop Up" function in EHR system ProfdocVision

4.2.2 The panel

All the physicians we spoke with were trilled and immediately liked the panel (Figure 22). This was something they needed. It was easy, not too much information and had good functionality. The functionality was close and they did not have to use many mouse clicks to get the information. A few physicians had some extra functions that were missed. Like history function and search function.

4.2.3 Configuration

When we spoke with the physicians, there was different view on how to configure such system. But one thing they agreed on, the ”Pop up” had to be configurable. Some wanted the ”pop up” to come every time there was a red

label information. Some of the practitioners wanted a function in order to configure how often this ”pop up” should be visible depending on the colours of the messages.

4.2.4 Red label

The red label (Figure 23) should contain information that was very important. Several physicians use the meningococcal meningitis as an example. They seemed to agree that this disease could have a serious outcome and that this information was urgent.

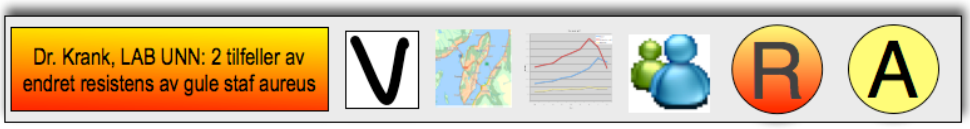


Figure 23 Red label with emergency message, identified micro organism, possible for resistance and other information

4.2.5 Yellow label

The yellow label (Figure 24) we use in connection with symptom base messages. The physicians said that this was what they expected. In Figure 24 we can see the yellow background with label text. This label was used to show symptom messages. The physicians had different views on when this label should pop up. There was no clear indication of how many times this should come up. Some of the informants wanted these just ones a day, other several time a day if the information was necessary, and some wanted this just once in a week. The physicians were afraid that these messages could appear too often.

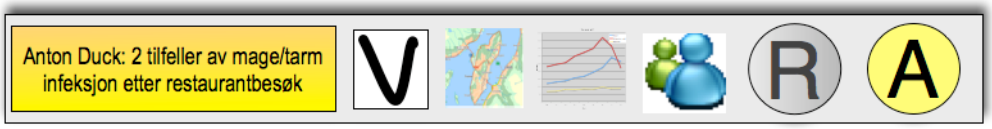


Figure 24 Yellow label where symptom based information are informing the physician

4.2.6 Green label

The green label was mentioned but only when an outbreak had passed. None of the interview objects though of using it for passing messages to each other. Some was positive to try to send information to the physicians responsible for infectious disease prevention in the municipality. No one had

any objection on this colour. See Figure 25 in history function.

4.2.7 The text

During the presentation name on doctors was used to indicate where the information was from. However, several of the physicians did not want any names of who sent the messages. It is vital that the text font and size are easy to read and been able to detect the right words. The text should also be combination of capital letters and non capital letters. (See Figure 23 and Figure 24 for example).

4.2.8 History function

In order to read history (Figure 25) of previous messages it should be possible to double click on the text with colour background. This way the user could see all previous messages or messages not deleted. Configuration of how long messages should stay in the system should be configurable by the user.

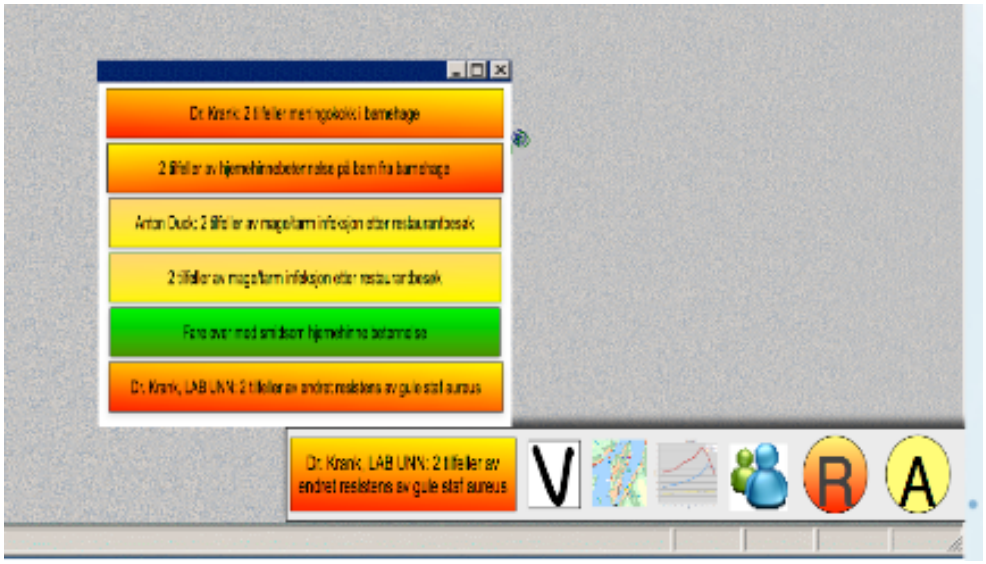


Figure 25 History function after clicking the red text. Also showing green label.

4.2.9 The confirm function

Some of the practitioners did not want to ”Click” on the ”V” (Figure 24) to mark that they had seen the message. However, others did not have any objections or express any opinion about this functionality. They seemed to accept the ”Click on the ”V” ” to mark that they have seen the messages.

One reason for this function is that the doctor reasonable for infectious disease prevention in the municipality to see whom had seen the ”important message”. In this light the system is collecting information for this function. Since there is divided opinion on this function, it might be a good idea to make this optional.

4.2.10 The search function

The search function was an interesting idea that came up during an interview. This functionality was not taken in consideration when the presentation was made. The search function should be like Google´s function. All of the most relevant things should come first. There should also be a configuration of where to search. Search sources could be mail, Internet or captured information and stored information related to the SBDS project.

4.2.11 Map

The primary care physicians all agreed on that maps are useful. There was a disagreement whether there should be an before and actual map. The before map was to say something about the normal situation. The actual map was to give the user information about how the situation for the epidemic was right now.

4.2.12 Charts

The chart that was shown at presentation did not give any special response. There was some comment that it should contain more information like time. Often the charts contained more information and were easier to watch. The primary care physicians preferred maps before charts. Some physicians wanted just one chart, but other accepted two charts with one in ”normal” condition and the ”present” condition. We did not have many parameters plotted on the chart, just three parameters, and there was a discussion whether there should be just one chart that present ”normal” and ”present” condition. This could of course depend on the disease or symptoms.

4.2.13 Resistance

The drug resistance presentation created engagement and received increased interest from all of the primary care physicians. They liked the presentation with the drug-panel and the combination with traffic lights. They saw the

similarity with the traffic and could easily see what kind of drug that was useful for the situation. They also liked the presentation where the drug the bacteria had developed resistance against were marked and therefore should not be used.

4.2.14 The ”A”

The “A” stands for “Additional Information”. The primary care physicians did not have any comment related to the “A” for other information. If food from a specific restaurant had infected a patient, then this could contain information related to the restaurants he had visited. The “A” could also be used for links to other websites. It could be an easy way for the user to find useful links connected to communicable diseases.

4.2.15 Phone vs. screen

Most of the physicians thought that they would not use phone as communication device during the consultants when the patient are in the office. They all preferred to use computer and computer screen over phone (Figure 26) since they all have the EHR-system there. The only use for phone could be during vacation, weekend or if they were out of office and something special happened. All agreed that this had to be configured by the user. All physicians seem to agree that ”red” messages could be sent when physicians are not in office.

Figure 26 Showing messages on phone, with links to map and charts.

4.2.16 Chatroom

The chat room was not a great thing they wanted. Most of the physicians did not use chat rooms. However, during some epidemic outbreak it can be useful. This was mainly not in focus for the primary care physicians, even if it was on the phone. One of the physicians thought this will be a way of communication between physicians, not just inside office, but thru several different medical offices when younger physicians enter the occupation.

4.2.17 Security

Every primary care physicians that we asked, seem to have no worries about security as long as there is no possibility of identifying the patient. The physicians seemed to have no problem with export of the diagnosis code and information typed into journal.
The trust of the system must be high and this is closely related to good logistic in the system, which can avoid false messages. All messages have to be true and be realistic and close to reality.

4.2.18 Automatic or manual

It seems that all physicians wanted an automatic export of information from their EHR-system. And this correlate with the other information the physicians gave. All tasks that can be automated are handy. The reason for doing this automatically is the lack of time and close time schedules among the primary care physicians, and they are afraid of anything that can consume more time.

4.2.19 Special requirements

The physician responsible for infectious disease prevention in the municipality had some other views than rest of the primary health physicians. This person wanted a possibility to see how many of the primary care physicians in his municipality that had received messages regarding outbreak or possible outbreak of contagious diseases. This is very important with regard to the most deadly diseases like meningococcal meningitis.

4.2.20 Other requirements

During the interview some of the physicians though that is could be a possibility to send personal message to each other or to the physicians responsible for contagious disease outbreak in the municipality. More like the Short Message Service (SMS) function on the cellular phone. This could be done just adding functionality on the palette like right click on specific message in history view and getting the chosen property.
There could be a “Send personal message” to one specific physician.

4.3 Summary

One of the main goals of this thesis was to establish requirement for prototyping the new symptom based surveillance disease system for primary health care physicians. This was done based on the interviews we did with the physicians.

The summaries of these requirements are short coloured messages with relevant text and valuable information that can be configured as each physicians wanted to avoid interrupts during consultation with patients. All messages should be sent to the workstation at the medical office where the physicians work. But occasionally it could be send to cellular phone. However, this must be configurable.

Chapter 5

5 Results

5.1 Introduction

This chapter presents the result that are collected and aggregated from the interviews. The interview started with presentation of the Symptom Based Disease Surveillance (SBDS) project.
The interviews started with a presentation of the project. When the interview session started we use question that had an intention to give information on some subject that we were focused on. At the end of each interview we gave a presentation of a possible interface for the user.

Requirement information is based on information that was collected during the interviews.

Complete presentations of visualization are showed in Appendix G.

5.1.1 The example used during interview

During the interview the outbreak of *Giarida Lamblia* in Bergen municipality was used. This outbreak caused over 1300 inhabitants to be infected and many patients got long-term illness or chronic disease from this micro organism. When we asked the physicians if they know or remembered this case, the answer we got was that 3 of 5 primary care health physicians remembered this case. Even if it was mentioned in the news on television and in the newspaper, some of the physicians did miss the information about this outbreak.

5.2 Collecting information, getting informed and report

The first part of the interview, the question was focus on how the situation was right now. How did the primary care physicians get their information? Who was giving them this information? And how did they actively collect information? Through these questions the intention was to know as much as possible about the information sources of the primary care physicians.

5.2.1 Collecting information

The physicians did mainly have the same routines to report the new incidences of diseases. Often this was done after the identification of bacteria or virus by the laboratory at the hospital. They received the information directly into their own Electronic Health Record (EHR)-system. But often the laboratory phoned in advanced. This is a routine the laboratory offer to their customers, in order to help the physicians to start treatment earlier.

5.2.1.1 Use of Internet

Most of the physicians used Internet, but rarely during the consultation with the patient. Occasionally this could be at help. Most of the physicians did have access to Internet from the office. One of the physicians did not use Internet in offices, cause lack of stable and fast communication lines. To use the Internet, this would take too much time and the computer probably would kneel because of the massive load of application.

5.2.1.2 Use of Norwegian Institute of Public Health (NIPH) WebPages

Just one of the physicians used the web pages and did this regularly. This was done with other colleagues in scheduled meeting. In this meeting the physicians discussed cases they have had since the last meeting. One of the ways to find information about these cases was to use the Internet for search. In this way the physicians got updated related to those cases. All of the physicians did know of these web pages. The other physicians used these web pages rarely. Just one did not use it at all. The reason for this was lack of Internet lines from workstation at office.

5.2.1.3 Use of MSIS-Web

The web pages where the user can pick up and make some reports of their own are well known among the physicians. But it is not that much in use. The main reason for that is that it is hard to use and the physicians have to use many clicks to reach the information they wanted. The physicians do not use these web pages during consultations. Additionally, the information on these pages was not that relevant to daily use.

5.2.1.4 Use of “www.Utbrudd.no”

Just one of the physicians knew these web pages. The rest did not know about it and therefore did not use it either. The reason why the physicians do

not know these web pages is unknown. Lack of marketing of this service could be one reason. It should be used more to report outbreak, but when it is unknown, the physicians cannot use it.

5.2.1.5 Other sources

The most used source of information by physicians is the colleagues. This is done directly thru phone, walk into the other physician's office or discuss issues during lunch break or meeting.
Also several physicians said that newspapers, TV-news or radio news could help them to get a picture of what was going on in the municipality, region or country regarding contagious diseases.

5.2.2 Getting information

Physicians do not always collect information about contagious diseases. Often the information is coming to them. They do not necessary need to search for it. This section list the sources of information used by the physicians.

5.2.2.1 Colleagues

Colleagues are the best source of information for primary care physicians on contagious diseases. They often have regular meetings where they discuss medical issues. In this meeting they often discuss issues that have recently happened. Some of the physicians together with colleagues use other information source during the meeting as Internet. Thru the meeting the physicians are getting more information and exchange experience.

5.2.2.2 The physicians responsible for infectious disease prevention in municipality

All physicians in the interviews said that the physicians that are responsible for the infectious disease prevention in the municipality had a central role of providing information.

All the physicians also said that this person would send information to them if necessary, and that have been done, and that he had a fairly good overview of the contagious disease situation in the municipality.

Some of the physicians call the physician responsible for the infectious disease prevention in municipality and tell about cases that are discovered or that they had suspicion about in advance, before a written report was sent.

Sometimes the physicians just ask if he have heard about other cases.

Some of the physicians did not use the phone much but rather use letters after confirming the disease.

The media is a channel that the physicians use. This information often comes to the physician when they accidentally are listening/watching to the media, reading something in magazines or just browsing medical professional literature. Often this can be a fast way of information about contagious diseases in other places in the country or in the world. In this media we also have put the magazines and paper that the medical association publishes.

5.2.3 Reporting

None of the physician's offices have advanced laboratory system to identify bacteria, virus, micro organism or traces of micro organism inside the human body. This is done when the physicians sent specimens sample to the laboratories (in Troms or Bodø). These laboratories have advanced systems to detect and specify each bacteria and other micro organism. The physicians receive laboratory reports after they have sent specimen samples. This is imported directly into the EHR-system at the medical office. The laboratory sends a form to the physicians after identified results that had to be reported as a service. In these situations the laboratory fills some of the form out and the physicians have to complete the form before it is sent to MSIS/NIPH.
However, the laboratories also have to send their part of the form to the MSIS/NIPH

5.2.4 International Classification of Primary Care (ICPC)

All physicians used the ICPC coding system. This is necessary in order to get paid from the public health care refunding system. The system is based on symptoms diagnosis and final diagnosis.

The reason for asking the physicians about this code system are that a new system need something to find what to search for and recognize symptoms caused by contagious diseases.

Several of the physicians said that the ICPC-code system is not good enough, and they use it because of the refunding payment. In many cases the ICPC system did not have good classification. The user had to use several

codes to describe the symptoms that are not done by the physicians. The reason for this is lack of time. Often the physicians give a symptom-based diagnosis, but never change even if they find something at the laboratory. The physicians changed diagnosis from symptom base to a finale diagnosis when the patient needed medicine, and they had to ad diagnosis on the prescriptions. Most of the physicians use just one diagnose occasionally they use several diagnoses.

In addition to the diagnosis code the physicians use notes in the EHR-system to add additional text about symptoms. In these text notes they use symptoms description as "Whopping cough", "Suspicion of Whopping cough" etc.

5.2.5 Visualization

This section in result will look at the response that we got during the interview with the physicians. They gave us many contributions on how and what kind of information they would like to have. Some of these is the result below is repeated data from the requirement parts.

The PowerPoint presentation (in Appendix G) of a possible visualization of a future system of symptom based surveillance system, was used to get information of what kind of information the physicians needed and how they wanted it presented and used. The SBDS project must evaluate the information regarding whether the project should use the visualisation or change it based on the information that we have found.

5.2.5.1 The panel

This is the key into the system. All the physicians seemed to like the panel or palette. This is the entrance to the system.

Some expressed the view of this palette and other just had no comment on it at all regarding to extra information and when to pop up. The physicians seem to like that the information did not take too much space and filled the screen. They also like that the text had different colour in background to indicate the priority of the messages. The physicians saw the palette as a warning sign that could act as a warning.

When this panel was showed, we told that this could be a pop-up function. It was some concern that this popup could appear in the wrong moment or situations and may turn the physicians out of focus. An example that was mentioned was if the physicians were in a conversation with a patient that

had suicide thoughts. And the point that was most discussed during the interview was when this should pop up. Some of the physicians said that the palette should pop up at curtain time during the day, once in a week, when turning the computer on, when leaving office or the user should start the program.

Some of the physicians wanted the panel to pop up when, the user was writing something that was related to a contagious disease in pre-diagnosis or in the text at EPR-system.

Several of the physicians were not happy to use the "V"-sign and click on this to indicate that the physicians have seen it. Even if this could help the primary care physicians in charge for contagious diseases control in municipality wanted this. They felt this could interrupt a consultation.

All the physician have the same view most serious disease messages should have red background The case on the presentation with meningitis was a good example. And they also agreed on that these messages should come at once.

The conclusion on the panel or palette is that it should be configurable by the user themselves. This would make the program more flexible.

5.2.5.2 The map

Most of the physicians seem to like the map. It needed more information to specify for how long time the information was collected. It could also hold information on date on each cases or time. One of the physicians did not want to say anything about the map. The physician had no experiences using map in such situation. Therefore it was hard to say anything which information that was needed.
Others said that it should be use two maps to indicate the normal situation and the current situations, as a snapshot of the contagion situation.

5.2.5.3 The Chart

The chart should have more information. The information that was missed was time period, day and time for each case of the meningitis. The chart could also be combined with maps and table.

5.2.5.4 Drug Resistance

Most of the physicians mention that Methicillin Resistant Staphylococcus Aureus (MRSA) was something that they were interested in when it come to

contagious diseases. But when we shown them the drug resistance panel with and without mark of changes in panel, they was not thrilled. They seem to found it OK, but nothing more. Some of the physicians said that this was useful information. However, some of the physicians said that they could not see the use of this because they got the information from the laboratory results. All physicians agreed that the traffic light was a good way of presenting the graduation of resistance.

5.2.5.5 Use of media

To see what kind of media the physicians used the presentation also contain cellular phone. On the phone the messages, maps, charts and both resistance slide was showed. This could represent the future use of this information. The physicians did not use the phone during the consultation to get information today. One of the physicians meant that phone was necessary for future use. In the future the physicians will need it to be kept updated. The phone will be more used in the future than today. This will happen when younger physicians that have been used cellular phone hole life becomes establish as physicians.

5.2.5.6 The most typical diseases

We ask the physicians which disease was most relevant to have in a prototype of a new system. There were no consensus on which diseases that were wanted. We saw some pattern that dangerous diseases like meningitis, legionnaire's disease, MRSA, influenza and influenza like diseases, some venereal diseases, and some diseases related to stomach and bowel??? diseases.

5.2.6 Future

The most obvious result we have found and that all of the physicians agreed on was that a new system has to give the information with less or equal cost of time they use today to find the same information. If they use one minute finding specific information, whether there is on paper or in the computer, then a new system should use less or equal than one minute. In addition the information have to true, relevant and meaningful and they must be able to use the information in practise right away.

5.3 Summary

The result we have showed that the physicians use Internet and do not use

the information on NIPH frequently. The most obvious source of information was colleagues in the medical office.

The physicians clearly pointed out that the ICPC code system is not good enough to use for detecting symptoms in the local EHR system. Additional information have to be used.

The visualization we had made had hit its target. The use of symbols, text and colour had a good effect on the visualization and the physicians had few objections on the visualization.

Every physician wanted to contribute to the project in the future if they were asked.

Chapter 6

6 Discussion

6.1 Introduction

In this chapter some of the potential problems related to a possible electronic symptom based surveillance system where information is shared among primary care physicians will be discussed.

Since this new Symptom Based Disease Surveillance (SBDS) project in northern Norway health region are not finish and we are just starting to collect information for the pilot phase, it would be hard or nearly impossible to foresee what the system will look like in the end. We have to assume that this system will be as close to our visualization as possible.

6.2 Major differences

6.2.1 Similarities

The SBSD project is different from other surveillance system in some way. However, there are some similarities. Like all the other system this project is collecting information from different sources. Norwegian Institute of Public Health (NIPH), Swedish Institute of Infection Disease Control (SIIDC) and this project are collecting information from the primary health care physicians and medical offices. Laboratory results are also included. As with other system this system is reporting possible disease outbreaks of communicable disease. The systems have an intention to deliver warnings that can help speeding up detection of communicable disease outbreaks.

6.2.2 Differences

The major differences between the SBSD project and other systems of surveillance of disease control systems are that this project mainly shares the information between the primary health care physicians. The system is supposed to send out information about occurrences of diseases in the local area. In addition this project intends to send reports to MSIS as well. This can be done after the pilot-phase. The system will not only send out warning of communicable diseases, but also messages about specific diseases that can

be possible to diagnose and that one or two cases have already been identified. In this case the system will act as an "advanced diagnosis support system" based on diagnosis and symptoms.

Sharing information on primary health care level

The system will act as a messenger among physicians in order to share information in near real time. Real time are depending how we define it. We will define real time, as a message is send, processed and presented, then this is real time. Normally in these other system we can see that information are able to be showed between 1-4 week after it is send either by paper or electronically. According to test that has been done in laboratory, it is possible to make a system that collects data from 50 sources and delivers messages within 4 seconds with updated epidemiological data that have been provided from EHR-systems (Bellika, Sue et al.).

Reporting across medical offices

All other system that we have seen is mainly reporting up to a higher authority or government, even if the information is collected from primary care physicians. We have seen that the reporting out of primary care physicians Electronic Health Record (EHR) system have been automatically or manually and been presented by web pages. Of course this system could pass on the messages to another surveillance system, but the main purpose in this project is to share the information among the primary health care physicians where the information is collected. In this case the information from one medical offices report to other medical offices what has happened there. This will make the information exchanging faster because it do not have to go to another places before it get published. However, on the other hand, these messages will increase the use of network and network resources.

Coordinating outbreaks

The SBSD system can support sending uniform message of information to the physicians from personnel that is coordinating contagious disease outbreaks. With this system the system can let physicians across medical offices communicate directly with each other. However, one person needs to be in charge of coordinating outbreaks. The most reasonable person to do this is the physician responsible for disease control in the municipality, but also other authorized personnel should be able to do this. This will ensure that messages are received and read by the physicians and it would be much faster than the system today, which mainly consists of phone, fax or mail. The person responsible for disease control in the municipalities should be able to send out messages about coordinating contagious disease outbreaks through the system.

6.3 Information collection and reporting

The reason for discussing this part is to show that physicians not necessarily use electronic solution even if they are new.

6.3.1 Knowing where to know

For decades the reporting system of contagious diseases has been available in healthcare. These systems have only been based on paper until recently. However, in 2005 the MSIS started the web pages for reporting of disease outbreak (www.utbrudd.no). This page is not much in use considering that there are just 173 registered users all over the country. If we assume that every physicians that work in primary care should be registered in this system, because they have an obligation to report outbreak even if they are off duty. We have at least 183 medical offices in northern Norway according to NOKLUS ((Noklus 2003), there are at least 183 physicians. But normally each office has at least 2-3 physicians working even on the small offices, the potentials of 400 physicians just in this part of the country. If we also consider that this region are the smallest of all the health regions in the country. Since there have been 5 regions since the opening of this service by MSIS, we should expect at least the same amount of physicians in every health region as in northern Norway, then we could expect that there are 1755 primary care physicians in Norway that should be registered. (Noklus 2005) This number is for sure underestimated. Then 9,9% of this underestimated figure is registered as users because NOKLUS work with medical offices that have laboratory functionality. Many medical offices do not have this functionality.
When we asked the physicians only one knew about these web pages. Then we can say for sure that these web pages are not well known among primary care physicians.
There could be several reasons for this. One is clear that this system has not been marketed, considering that all of the physicians we asked have read the paper based MSIS report or sometime used the MSIS report on web. Another reason can be that physicians do not feel they have the responsibility and they think this is a task for the doctor in charge of infection disease control in the municipality. Some of the physicians we interviewed felt it like this. Another issue that can contribute to the lack of users at www.utbrudd.no are that the physicians still can use the old paper based system along with the pages. The physicians and the medical offices have established procedures for reporting to MSIS and others on paper based solution and have not taken the new solution into use. MSIS have in their own report listed some reason why the web page is not used. Short summaries are in MSIS report 9/2007

issues some improvement regarding the www.utbrudd.no. This report is also pointing out where to make improvement. Among these improvements are increased usefulness as better reporting procedures, more automate functionality and ease of use. Hpwever, in the long run, the information about contagious disease outbreak has to be brought to the physicians.

It could also be that there is a division of work within the medical office related to the work and between the medical office and laboratories. Since the report is first filled out at the laboratory that analyzed the sample, they are starting the chain of reporting. They start this by sending out an electronic laboratory report to the physician that sent the sample. These laboratory reports are received in the electronic health record at the medical office. In addition the laboratory are sending the MSIS report on paper to the physician's office, the office staff receives the paper and transfer it to the physician. After the physicians have added extra information on the form, he sends it back to the office staff and they send the report to MSIS. By removing all use of paper to electronically reporting, it will be possible to improve quality and the frequency of reporting. This can be done by using more marketing instruments and cooperate with the medical association in Norway to find all medical physicians that are registered.

The use of the information on MSIS, SIIDC and other sites that present information about communicable diseases are difficult to use. The users have to use many "click" to reach these web pages. Often the resolution is not good enough. The physicians have to use time to find the different web pages and have to pass other pages in order to get the web page they wanted. However, the information is relevant enough, but unfortunately out of date. The time gap between when diseases are registered and the time it is visualized are too long.
Many of these disadvantages with systems of today can be avoided by offering the information in the users own environment. This will cut the time to search and find the right pages. The user will feel the information is more relevant. By making all reporting to this system electronically, it will improve the quality and quantity.

6.4 Obtaining sustainable use

In this section we will discuss how a new system for symptom based surveillance solution system can be used to obtain sustainable use. We will also discuss problems around this kind of systems that can affect the use of the system.

6.4.1 User experience

All the physicians have used electronic health records for a long time. They are experienced with the use of a computer. Since all of the medical offices in north Norway use EHR systems, we can expect that all physicians use EHR in their daily work.

6.4.2 Short of time

All of the physicians have tight time schedules at work. In two cases the informants were able to take the interview within office hours. The other tree we had to do outside of office hours. The physicians have calculated how much time they have to use on every patient. If a patient use more time than calculated, the physicians have to cut down on the next patent, meeting or lunch. But sometimes the physicians just have to let the rest of patients that day have to wait in the queue. The tight time schedule the physicians in primary care experience are essential if they would like to start using new tools in practice. Several physicians reported that they have been asked to contribute to projects with filling out extra forms, but they did not participate because it would take too much time. Even if this activity just was supposed to take a minute or two. The physicians we asked said directly that if participating in a project implied spending some extra minutes, then they would drop participating in the project.

This issue will have an impact on every new tool that is supposed to help the physician. All good decision making tools will have to take the time issue into deep consideration. This has to be kept in mind when the SBDS project will try to deploy a new system among primary care physicians.

The time issue are also present when the new symptom based contagious disease system are trying to reduce the time from when it is possible to diagnose the first sample or symptoms of contagious disease outbreaks to a detection of an outbreak without a symptom based system.

One of the physicians we interviewed was concerned about the time issue and the value of the information that the system could give. He was comparing when he was attending a conference and he had learned something new like a new procedure. The new procedure he had learned had to so useful that he should be able to use it in his own practice the very next day. If the new procedures are supposed to replace another, then this procedure should use less time than the old one.

This statement is fitting into the “Usefulness of medical information” in the

theory part in this thesis. This new system has to give useful information based on validity and relevance in the context of contagious diseases.
In addition the work have to be minimal or less than what the physicians use today to collect this kind of information. If the new surveillance system succeeds in achieving this, then the SBDS project can have success among primary care physicians.

6.4.3 Validity of information

The validity of information in a system as this new SBDS system are essential. The information it gives to the user are messages that show up as "pop up" (see Figure 23 and Figure 24). The users are willing to try this system. When we ask the physicians if they would like to participate in the pilot phase, they all agree. We then assume they are willing to test such a system and that they want to be involved in developing the system. This can be done because they trust that the methods for detection are good and reliable. But a trust as this will not last forever. The users will evaluate the information from the system. When they receive messages that report outbreaks, these outbreaks can be false or true. If there are too many false messages of outbreaks the physicians will turn of the system. A study concluded with innovative surveillance methods can be increasingly helpful detecting outbreaks (Smolinski, Hamburg et al. 2003), (Buehler 2004). Having good methods for detecting correct outbreaks will motivate the users to continue using the system. All surveillance systems should also be evaluated regularly, in order to confirm that the systems deliver what they are expected to deliver. This will also help the physicians to rely on the information the SBDS distribute.

6.5 ICPC (International Classification of Primary Care)

The government and the physician have adopted the Norwegian ICPC code systems from KITH (Norwegian Centre for Informatics in Health and Social Care). The ICPC code system is the only description of diseases in primary care that are accepted by the government. This code system is supposed to be used in the SBDS project. The SBSD system intends to extract every ICPC code that was registered and pass it on to other physicians. If there was enough symptom or diseases registered, then the system would send out warnings of possible contagious disease outbreaks. But this would not work by just using the ICPC code system. The reason for this are that the ICPC code system are not god enough for classifying symptoms and in some case diseases. We can see this with symptoms related to the respiratory symptoms

or diseases. This was pointed out when we interviewed the physicians. Several of these saw limitations of this coding system. One way of avoiding this problem is to start using text search in the electronic health record. Normally the physicians write something in the journal-notes related to symptoms during the consultation. If these notes were structured and categorized and describe the symptoms the patient have, the SBDS system could in some way get this information from the health record and do analyses on these data in order to make messages. By making this walk around a bad classification problem in the ICPC-code, it might be a good idea to make the text in the journal-notes structured, so it can be used in the SBDS project. This will of course depend on the physicians and their goodwill. The vendor of the electronic health record in primary care must contribute and share these notes and ICPC code to the SBDS system. In addition there have to be a common way of describing the symptom and diseases among the physicians. This again will imply that the physicians agree on a set of common terms. If the project wanted to do this, then it can be a challenge to reach a common agreement, taken into consideration that this can involve over 200 physicians in the northern part of Norway. Another solution can be to ask KITH to expand the ICPC-code system to include more specific symptoms and diagnosis where this is missing in the ICPC code system. Additional the government do need to approve this change of the code system, since this will have an effect on the economy of the physicians.

6.6 Visualizing

In this section we will discuss the problem related to visualization within the symptom based disease surveillance system.

Evaluation of surveillance system for early detection of outbreaks

6.6.1 Information overload

During the presentation of visualization, the physicians often complained about information overload when they start searching on the Internet. It often ended up with passing a lot of web pages before they find the information they needed or wanted. So usually they did not use the Internet for searching during consultation, just occasionally. Some of the physicians use the Internet during meeting with other colleagues. In this case they could use the Internet and was often browsing different web pages. But some of these were used more than others. We did not ask in which cases they used the Internet or if it was just for update of their knowledge. According to a recent study physicals used Google to search for diagnosis on Internet for difficult

cases(Hangwi Tang 2006). In 15 of 26 cases the Google search engine found the correct diagnosis. This shows that physicians will in some cases use the Internet, Google and search to establish a diagnosis (Hangwi Tang 2006) (Hangwi Tang 2006). It seems though that the physicians we asked, have not taken this possible source of information into use. None of the physician we asked used the Internet to search for information about diseases during consultation. The closest to use of Internet was that this could be done with colleagues during meeting where they discuss unusual or particularly cases. In the future the Internet will be more used for searching and diagnosing the most difficulties cases (ibid). The SBDS project should also build an Internet search engine into the system, but it should also include the physicians own EHR.

Another form of information overload was when we show the presentation of the yellow labelled messages. Nearly all of these physicians we spoke with were afraid getting overloaded with this kind of information and wanted to have a configuration option in order to manage when these messages should appear. This can cause problem if there are important messages that can be missed. On physicians wanted to just have this once in a week. But other wanted it on daily basis. If the messages appear just once in a week, it can be hard to relate messages to specific symptom a patient had have that week. And if one of these messages should fit to a patient, the physician had to recall which patient it was, then find this patient's health record and see if this fits to what he remembered. If the messages are coming only once a day, then there is better chance that the physicians recall which patient, and more easier can find his health record. The SBDS project should let the physicians themselves be able to configure the ON/OFF and how and when the messages should be visualized for the physicians.

6.6.2 Information at the right time

The physicians we discussed with during the visualization, they often pointed out that they did not want to use many sources of information during consultation. The reasons were lack of time and fear of using too much time behind the screen. And as result of this they needed the right information at the right time. In this context they did not want to search for information. They wanted the information to be automatically displayed. The SBDS is supposed to make warning about the different contagious diseases that are registered in the local area. If there were one or two cases with suspicion of meningitis, this information was something they wanted access to immediately. This information should be available in their system at once. Information as if there was a meningitis outbreak in the municipality was

essential. They accepted to get this information at any time, even during consultation with patient. But on the other hand it is vital that even if the information is given during a consultation, it had to be given discreet and quiet. As a physician said, “I might be in a consultation with a patient with suicidal tendency” then he would not want to be interrupted by having to click on “confirm” message button on the screen of his computer.

6.6.3 Perceived ease of use

When starting to develop an electronic symptom based surveillance system there are many functions that can be needed or wished. In our interviews with the physicians the requirements was not always the same and we did not discover a general agreement among the physicians on all requirements. This is natural because each individual have build up different ways of performing their profession. Therefore there should be different opinions on how the visualization should be. But taken into consideration this, it was amazing that they did not have any strong disagreement on how the information and visualization that was presented. When we asked if we were on the right track the physicians agreed. The discussion was mainly on how to be able to configure the system to meet the individual needs. The main objects as pop up function, text, resistance, colour, use of map, use of graph and history function was very easy constructed with just needed functionality in mind. This was something the physicians felt comfortable with. The main reason for making the visualization with just needed functionality was increasing the value of information by removing unnecessary information and presenting relevant information in context.

The access to the information has to be easy. Perceived ease of use is one of the parameters in the Technology Acceptance Model (TAM) theory that fit into this situation with SBDS and the visualization. According to the TAM model the ease of use are affecting the attitude toward using, which again affects the behavioural intention to use.

6.6.4 Perceived usefulness

The physicians accepted the visualization we used in the presentation during the interviews. The physicians themselves often used the same example of contagious diseases before we presented it in the visualization. The reason for this can be that this example is obvious and something that most physicians look for. Then this will feel naturally for the physicians to use the same examples. On the other hand these examples are so important that it is

hard to miss them. This was the case with the meningitis example. This disease was used in the presentation of visualization and often mentioned before it was used in the presentation.

Other issues that will affect the finale use of the new system are whether the system gives valuable information that is highly used in the practice by the physicians. To produce this information the system must use all sources and analyse the contents of these and produce messages that are the truth. By truth we mean that it is a very high probability that this messages are based on the same that the physicians experience. This experience must either be experienced by the physician himself or thru conversation with colleagues or in conversation with the patients. The most likely source of information to tell the truth is the information and diagnosis of patients. After this source of information together with information from colleagues will make a picture that reflects what's out there of contagious diseases. If the system provides the physicians with the same information that he experience in contact with his sources of information, then he will start trusting the new system.

All these information are related to the value of the information that the physicians can obtain. And the TAM model in chapter 2 shows that there is a high probability that the new system will be used, if the information is correct and valuable.

6.7 Summary

The SBSD project has many similarities with other surveillance system on early detection of outbreak. The sources are in most cases the same, but it divides from other system when it comes to sharing the information and reporting of the information. It also divides from MSIS and others since it bring the information to the physician instead of the physician have to go out and seek for the information. In this way the SBDS project are moving the information closer to the user of the information.
The physician's time is valuable and validity of information is essential for the physician and this have to be in front of every aspect of the development of the project. These aspects are important when we think about sustainable use of the system by the physicians.
It is important that the physicians do not get overloaded with information when the system visualizes information. It is necessary that the physicians can themselves decide when the information from the SBDS system should appear. It is also important that the physician have control over the interruptions these messages can create. The physicians need to be able to decide whether the system can interrupt during a consultation. The

information should not take much time to read or understand. The SBDS system should make it easy to get further information related to the messages, within just one or two clicks.
The information giving to the physicians have to be made available in an easy way that gives the physicians short messages that contain valuable information. They also need to be able to further explore interesting and useful messages, especially when the information is relevant to the consultations.

Chapter 7

7 Concluding Remarks

7.1 Introduction

This chapter contains the final conclusion for visualization in the symptom based disease surveillance system as well as a short discussion of further work. However, we will start with a critical view on our own work.

7.2 Conclusion

This thesis has limitations. One of the biggest limitations is the availability of primary care physicians that we could interview. It is hard to get thru to the physicians in primary care sector to get interviews. The physicians have limited time available and they want to use as much time with patients as possible. We are very grateful for the primary care physicians that helped us. However, we wish that we could interview more physicians and have more feedback on the visualization. However, we think that the primary care physicians we spoke with are representative for the majority of the physicians in Tromsø municipality. The views they had were reasonable and will not be far from the rest of the physicians we believe. Since we have interviewed the physicians responsible for communicable diseases in Tromsø municipality we got a clear view on what is important in some issues related to contagious diseases and contagious disease outbreaks. This person has a huge contact network with other physicians in the municipality, which help us get a clear view on how the physicians report contagious diseases. It also helped us find important diseases that could be reasonable to focus on in a pilot phase of the SBDS project.

Related to the primary research question in chapter one where we asked if the visualization of information related to communicable diseases we have thru the theory and the interviews found that by putting the information close to the physicians thru the SBDS project this will help the primary care physicians to determinate whether there is a communicable disease outbreak with the information shared between the physicians across the medical offices. The SBDS system can help primary care physician by getting information faster than they do today. Thru the visualization it show that the information to the physician have to be short, easy recognisable and must not interrupt the consultations with other patients. The information guide that follows the messages to the physicians must be easy to use and contain more

information related to the messages, if the physicians wants more information. The SBDS project should also let the physicians themselves decide when the interruption of the messages should happen. By putting this information close the physicians to their own electronic health record (EHR) system as they use today, this will ensure sustainable use of the SBDS system. This requires close cooperative work with the vendors of electronic health records. Thru the interviews we also found that the ease of use and information usefulness are essential for sustainable use of the system. The most relevant contagious disease outbreaks they want information on are those diseases that are most dangerous as meningitis, legionnaires disease, whooping cough, influenza like diseases and diseases related to drug resistant micro organism. The messages related to the most dangerous diseases need to be presented to the physicians right away but the other messages should be present only when the physicians wanted. The study also shows that the ICPC classifications system is not good enough to be used unchanged. The ICPC classification system can be used in combination with the local EHR used in the medical office.

All the physicians we interviewed wanted to contribute to the future of the SBDS project. This shows that if a system can help the physicians to get more valuable information, they will use time on projects like this.

7.3 Future work

The future work of the Symptom Based Disease Surveillance (SBDS) is very much depending on contribution from the physicians. The system can only be a success if they are participating and give good feedback during the prototyping period.

In the future the SBDS system should be able to use information inside the SBDS and the electronic health record system to collect information that are context sensitive to the information in the messages but also do research for the physicians and bring it to his desktop in a easy and simple way. The research could be like the Google search, but more selective and add just information that are related to the patient and issues that is highlighted in the local area.

In addition the authority reports from laboratory to Norwegian Institute for Public Health (NIPH), from laboratory to primary health care physicians and from the primary health care physician to NIPH should be electronic. See Figure 7 for overview of this report system that should be done by messages as laboratory reports is done today. Today NIPH offers a web page (www.utbrudd.no) that the users don't use or don't know about. If this is

done electronically this will increase the quality and quantity of the authority reporting. By doing this electronically the laboratory and the primary care physicians could be able to increase efficiency in the routines on both places. The hospital could use their laboratory system to create the messages instead of using paper, and the primary care physicians will receive this messages at the same time as he receive the lab report in his own electronic health record. The physician can add information that is needed before he passes it on to NIPH. The SBDS system could read these messages before it enters the local electronic health record in medical office, which also can be done with laboratory reports.

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Appendix

Appendix A

Overview of diseases that had to be reported to MSIS of group A.

Group A
Sykdommer som forebygges gjennom Barnevaksinasjons-programmet
Virushepatitter
Mat- og vannbårne sykdommer
Zoonoser
Alvorlige, importsykdommer
Alvorlige miljøsykdommer
Alvorlige, systemiske sykdommer
Sykdommer forårsaket av visse resistente bakterier
Sykdommer som forebygges gjennom Barnevaksinasjons-programmet
Diphtheria
Whooping cough
Mumps
Measles sibst.
Polio
German measles
Haemophilus influenzae
Tetanus
Tuberculosis
Hepatitt A
Hepatitt B
Hepatitt C
Mat- og vannbårne sykdommer
Botulisme
Campylobacteriose
E.coli-enteritt
Giardiasis
Listeriose
Salmonellose
Yersiniose
Zoonoser
Brucellose
Ekinokokkose
Lyme borreliose
Miltbrann
Nephropathia epidemica
Rabies

Trikinose
Tularemi
Alvorlige, importsykdommer
Flekktyfus
Gulfeber
Hemoragisk feber
Cholera
Lepra
Malaria
Plague/Pest
Shigellos
Tilbakefallsfeber
Alvorlige miljøsykdommer
Atypisk mykobakterieinfeksjon
Legionnare´s disease
Serious systemic diseases
Aids
Alvorlig, akutt luftveissyndrom - sars
Encefalitt
Kopper
Paratyfoidfeber
Prionsykdommer
Systemisk meningokokksykdom
Systemisk pneumokokksykdom
Systemisk gruppe A streptokokksykdom
Systemisk gruppe B streptokokksykdom
Tyfoidfeber
Sykdommer eller bærertilstander forårsaket av visse resistente bakterier
Smittebærertilstand eller infeksjoner med meticillinresistente gule stafylokokker
Smittebærertilstand eller infeksjoner med penicillinresistente pneumokokker
Smittebærertilstand eller infeksjoner med vankomycinresistente enterokokker

Appendix B

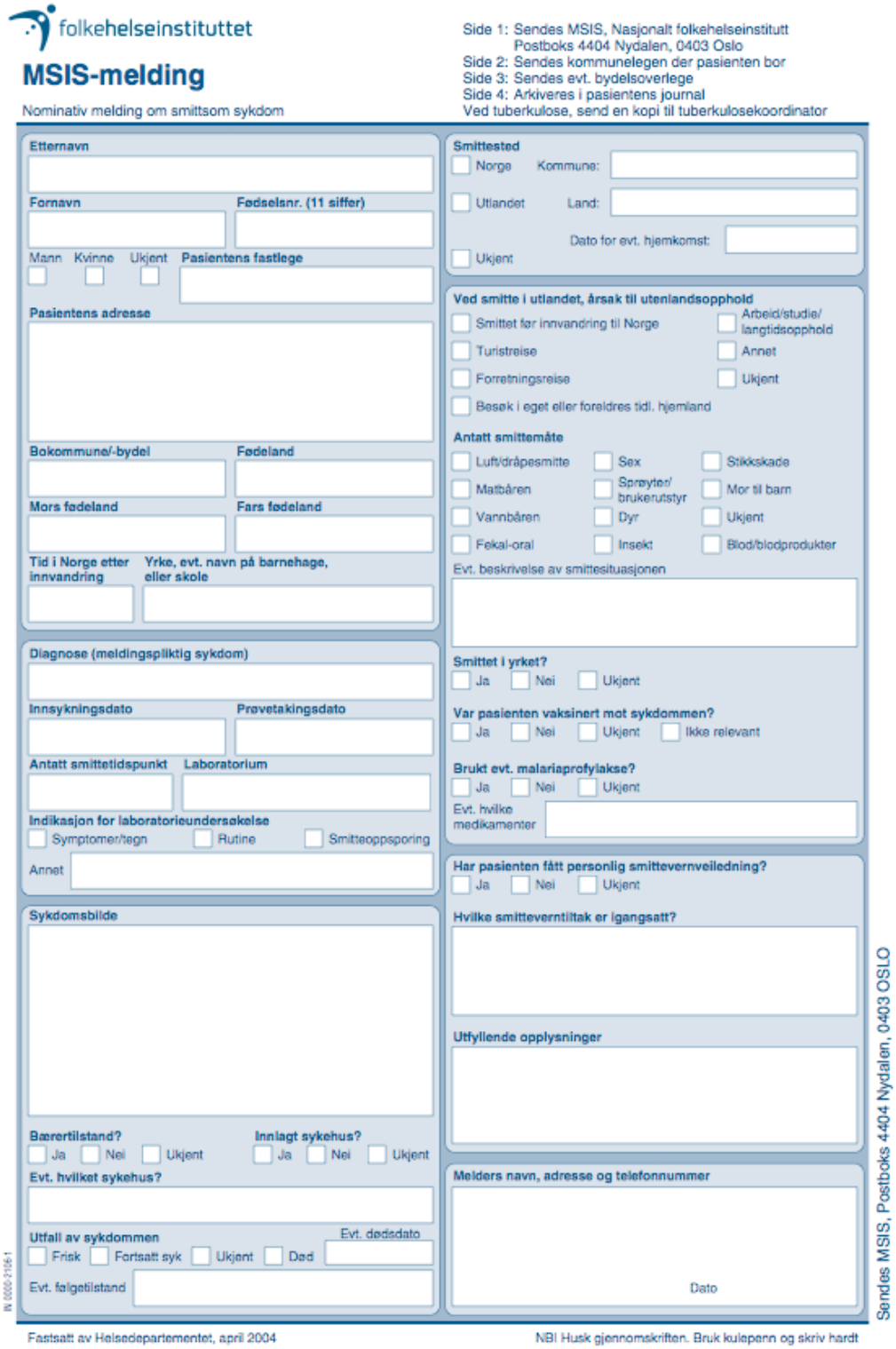
Group B
Gonorrhoea
Hiv-infection
Syphilis

Appendix C

Group C
Genital chlamydiainfection
Influenza like diseases
Influenza

Appendix D

The report form for MSIS group A.



folkehelseinstituttet

MSIS-melding

Nominativ melding om smittsom sykdom

Side 1: Sendes MSIS, Nasjonalt folkehelseinstitutt
Postboks 4404 Nydalen, 0403 Oslo
Side 2: Sendes kommunelegen der pasienten bor
Side 3: Sendes evt. bydelsoverlege
Side 4: Arkiveres i pasientens journal
Ved tuberkulose, send en kopi til tuberkulosekoordinator

Etternavn

Fornavn | Fødselsnr. (11 siffer)

Mann | Kvinne | Ukjent | Pasientens fastlege

Pasientens adresse

Bokommune/-bydel | Fødeland

Mors fødeland | Fars fødeland

Tid i Norge etter innvandring | Yrke, evt. navn på barnehage, eller skole

Diagnose (meldingspliktig sykdom)

Innsykningsdato | Prøvetakingsdato

Antatt smittetidspunkt | Laboratorium

Indikasjon for laboratorieundersøkelse
Symptomer/tegn | Rutine | Smitteoppsporing

Annet

Sykdomsbilde

Bæretilstand? Ja | Nei | Ukjent

Innlagt sykehus? Ja | Nei | Ukjent

Evt. hvilket sykehus?

Utfall av sykdommen
Frisk | Fortsatt syk | Ukjent | Død | Evt. dødsdato

Evt. følgetilstand

Smittested
Norge | Kommune:
Utlandet | Land:
Dato for evt. hjemkomst:
Ukjent

Ved smitte i utlandet, årsak til utenlandsopphold
Smittet før innvandring til Norge | Arbeid/studie/langtidsopphold
Turistreise | Annet
Forretningsreise | Ukjent
Besøk i eget eller foreldres tidl. hjemland

Antatt smittemåte
Luft/dråpesmitte | Sex | Stikkskade
Matbåren | Sprøyte/brukerutstyr | Mor til barn
Vannbåren | Dyr | Ukjent
Fekal-oral | Insekt | Blod/blodprodukter

Evt. beskrivelse av smittesituasjonen

Smittet i yrket? Ja | Nei | Ukjent

Var pasienten vaksinert mot sykdommen? Ja | Nei | Ukjent | Ikke relevant

Brukt evt. malariaprofylakse? Ja | Nei | Ukjent

Evt. hvilke medikamenter

Har pasienten fått personlig smittevernveiledning? Ja | Nei | Ukjent

Hvilke smitteverntiltak er igangsatt?

Utfyllende opplysninger

Melders navn, adresse og telefonnummer

Dato

Sendes MSIS, Postboks 4404 Nydalen, 0403 OSLO

IN 0000-2106:1

Fastsatt av Helsedepartementet, april 2004

NB! Husk gjennomskriften. Bruk kulepenn og skriv hardt

- **Appendix E**

Samtykkeerklæring

Til informanten
Nasjonalt Senter for Telemedisin (NST) er en forsknings- og utviklingsavdeling ved Universitetssykehuset i Nord-Norge (UNN), som arbeider med utvikling, utprøving og evaluering av informasjons- og kommunikasjonsteknologi i helsevesenet. NST har gjennom Telemedisinsk Forskningsutvalg i Helse Nord fått midler til forskningsprosjektet "Symptombasert sykdomsovervåkning i Helse Nord". **Prosjektets mål er å undersøke effektene av å dele informasjon om smittesituasjonen mellom primærleger. Endrer dette klinisk praksis med hensyn til testing for, diagnostisering og behandling av smittsomme sykdommer**? For å realisere målene skal prosjektet fremskaffe verktøy for automatisk uttrekk og utveksling av smitteinformasjon mellom primærlegene, og verktøy for bearbeidelse, presentasjon og tidlig varsling av utbrudd.

Vi er interessert i dine opplevelser og erfaringer rundt bruk av eksisterende tjenester fra Folkehelseinstituttet, samt dine krav, råd og vurderinger i forhold til et fremtidig "Symptombaser sykdomsovervåkningssystem". En intervjuguide vil danne utgangspunkt for samtalen, men samtalen vil være åpen for momenter du finner relevant i denne sammenhengen. Intervjuene utgjør hovedkilden for data, og vil vare ca. 45 minutter. Intervjuene vil i hovedsak bli foretatt på ettermiddagstid.

Deltakelsen er frivillig og du kan når som helst trekke deg fra prosjektet. Informasjonen som kommer fram vil bli behandlet konfidensielt og presentert på en måte som gjør at de enkeltes svar ikke kan identifiseres.

Intervjuene vil bli tatt opp på lydbånd. Deretter blir intervjuet skrevet inn på PC av intervjuer eller en sekretær. Datafilene blir ikke identifisert ved navn, men ved nummer og vil lagres på et sikkert sted. Kobling mellom navn og nummer, samt lydbåndet og evt utskrifter av intervjuet holdes innelåst ved NST. Samtykkeerklæringen holdes avskilt fra utskriften og lydbåndene. Dersom direkte sitat skal brukes vil de ikke vise direkte til personer, men de skal illustrere poeng knyttet til analysen. Dataene blir dermed anonymisert.

Ved å skrive under på denne erklæringen gir du ditt samtykke til å være informant i prosjektet og til at informasjon blir behandlet slik som beskrevet over. Du kan når som helst fritt trekke tilbake dette samtykket og informasjon som måtte være innhentet vil da bli slettet.

Dato:……Navn:……

Appendix F

This is the complete liste of questing that was used in the interviews. This list is in norwegian.

Formål/hensikt med spørreundersøkelsen

Prosjektet mål er å undersøke effektene av å dele informasjon om smittesituasjonen mellom primærleger. Endrer dette klinisk praksis med hensyn til testing for, diagnostisering og behandling av smittsomme sykdommer? For å realisere målene skal prosjektet fremskaffes verktøy for automatisk uttrekk og utveksling av smitteinformasjon mellom primærlegene, og verktøy for bearbeidelse, presentasjon og tidlig varsling av utbrudd.

Hensikten med dette intervjuet / denne spørre undersøkelsen er:

- Å sette deg som primærlege i førersete mht utforming av systemet
- Å avdekke hva som blir avgjørende for at systemet skal bli et nyttig verktøy for deg
- Å avdekke konkret hva du har – og ikke har behov for (hvilken type informasjon, hvorfor, og hvordan bør den presenteres)
- Å avdekke hva som skal til for at du skal føle seg trygge på systemet

Kartlegging av nå-situasjonen:

Hvordan innrapporteres funn av smittsomme sykdommer i dag?

1. **Hvilke rutiner for innrapporteringer til MSIS praktiserer ditt legekontor?**

Hvordan blir du informert, og hvordan innhenter du selv informasjon om smittsomme sykdommer i dag?

Hva mottar du av informasjon fra andre mht smittsomme sykdommer? Hvor relevant/viktig er denne infomasjonen?
Hva innhenter du selv, fra hvor? Hvor viktig er denne informasjonen?

2. **Forventer du at smittevernsoverlegen (evt kommunelegen) har en fullstendig oversikt over forekomsten av smittsomme sykdommer i din kommune, og varsler deg mht hva du trenger å vite?**

3. **Får du nødvendig informasjon (riktig informasjon til riktig tid) om smittsomme sykdommer ut fra de kanaler som eksisterer i dag?**

4. **Har du brukt og bruker du www.MSIS.no? Erfaringer?**

5. **Har du brukt det internettbaserte varslingssystemet for utbrudd (www.utbrudd.no)?**

6. **Har du brukt og bruker du www.fhi.no og deres MSIS-rapporter**

7. **Dersom du ikke bruker MSIS-web, fhi og utbruddvarsling?**
   a. Hvorfor?
   b. Oppløsning/oppdateringsfrekvens?
   c. Tilgang?
   d. Andre ting

Hvordan kan du bruke dagens system til å detektere fastslå/oppdage et utbrudd av smittsomme sykdommer/epidemier?

8. **Beskriv hvordan du kan bruke dagens system til å detektere /fastslå/oppdage et sykdomsutbrudd/ en epidemi?**

Hvordan bruker du ICPC-kodene mht symptomer og diagnoser for smittsomme sykdommer?

9. **Dine erfaringer med ICPC-systemet (gjelder dine diagnoser/kliniske funn)?**
   e. Fortell hvordan du bruker ICPC?

   f. Bruker du å sette flere ICPC diagnoser på samme pasient?
      i. Hvordan kombinerer du disse?
      ii. Bare flere symptombaserte?

   g. Når du bare angir pasientens symptomer, hvor mange angir du: Alle, de viktigste, den viktigste

10. **Hvor egnet er ICPC for symptombasert overvåkning**

Kartlegging av ønsket situasjon / kravspec:

Dersom vi skal etablere et symptombasert overvåkningssystem hvor en deler informasjon om smittesituasjonen mellom primærleger, hvordan skal systemet være for at det skal oppleves nyttig, og for at du skal bruke det?

11. **Hvordan ser du på deling av informasjon mellom primærleger**

basert på automatisk uttrekk fra journalen?

12. **Hvilke smittsomme sykdommer mener du ville det være nyttigst/viktigst å overvåke?**

13. **Annen informasjon som kan være nyttig/relevant å utveksle mellom primærleger, e ler innhente fra laboratorier eller sykehus, eks resistensdata**

Frekvens, område, spredning + + - alt dette kan vi ta under presentasjon av grensesnittene

14. ***Hvor hyppig ønsker du å kunne bli informert om en smittesituasjon?***
    - *h. Kunne innhente oppdatert informasjon til enhver tid/ sanntid??*
    - *i. Varsles når ny smittesituasjon oppstår??*

15. ***Dersom du er blitt informert om at en smittesituasjon er til stede, hvor hyppig ønsker du å bli oppdatert på situasjonen***
    - *j. Hver gang den endrer seg*
    - *k. Daglig*
    - *l. Ukentlig*

16. ***Hvor hyppig bør en varsle/påminne om at en smittesituasjon fortsatt er tilstede dersom den er stabil?***

17. ***Dersom du aktivt skal be om / innhente oversikt over sykdomsutbrudd, hvor vidt/bredt er det interessant å orientere seg***
    - *m. Kommune*
    - *n. Nabokommuner*
    - *o. Region*
    - *p. Ta med storbyene*
    - *q. Nasjonalt*
    - *r. Internasjonalt*
    - *s. Annet*

18. ***Dersom det er mulig å fremskaffe informasjon om hvordan en sykdom ser ut til å ville spre seg, på hvilke måte ønsker du å få presentert denne informasjonen, og hvor hyppig?***

    t. Hvor viktig er det å kunne svare på ”Hva går doktor”?

19. **Hvilke fordeler ser du med elektronisk og automatisk symtombasert overvåkning og varsling i forhold til dagens system?**

20. **Hvilke svakheter/ulemper ser du med elektronisk og automatisk symtombasert overvåkning og varsling i forhold til dagens system?**

21. **Kan nøyaktig og oppdatert informasjon om smittsomme sykdommer i forkant av en epidemi hjelpe deg til å ta de riktige prøvene?**

22. **Kan nøyaktig og oppdatert informasjon om smittsomme sykdommer i forkant av en epidemi i så måte kunne redusere sykelighet (forutsetter at sykdommen både oppdages og kan behandles helt eller delvis, i alle fall at symptomene reduseres) og dødelighet?**

23. **Har du noen betenkeligheter mht sikkerhet til et slikt system?**

24. Kan du tenke deg å være med å prøve ut en slik løsning??

25. Innstilling i forhold til å delta i en faglig epidemiologigruppe (smågruppe) knyttet til prosjektet? Er det en forutsetning at det blir godkjent av legeforeningen som faglig kvalifiserende /-oppdatering?

Appendix G

This appendix contain the complete presentation of visualization for physicians.

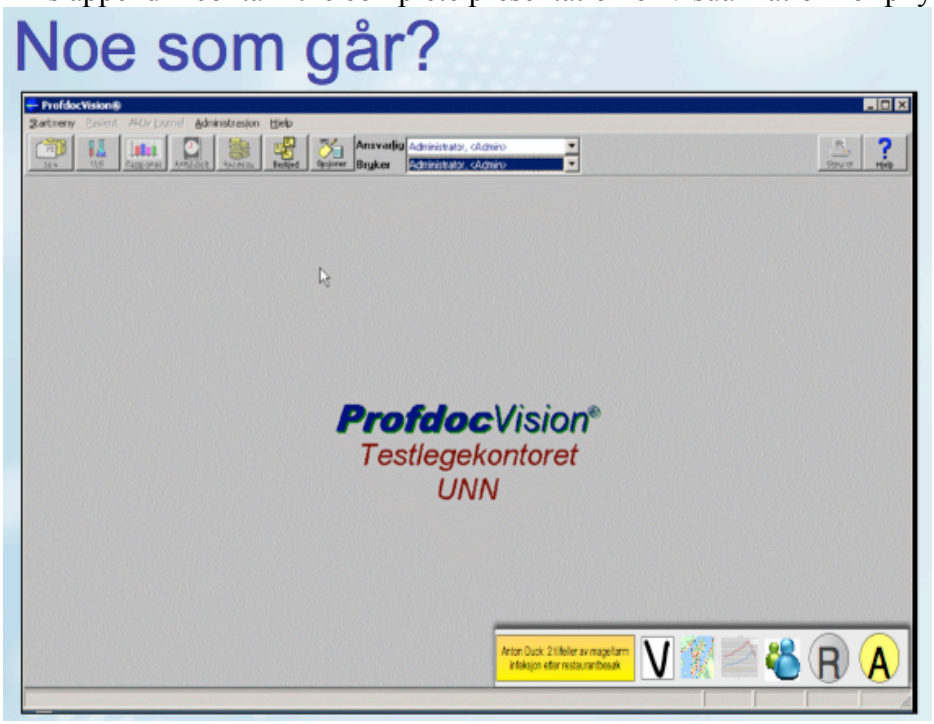
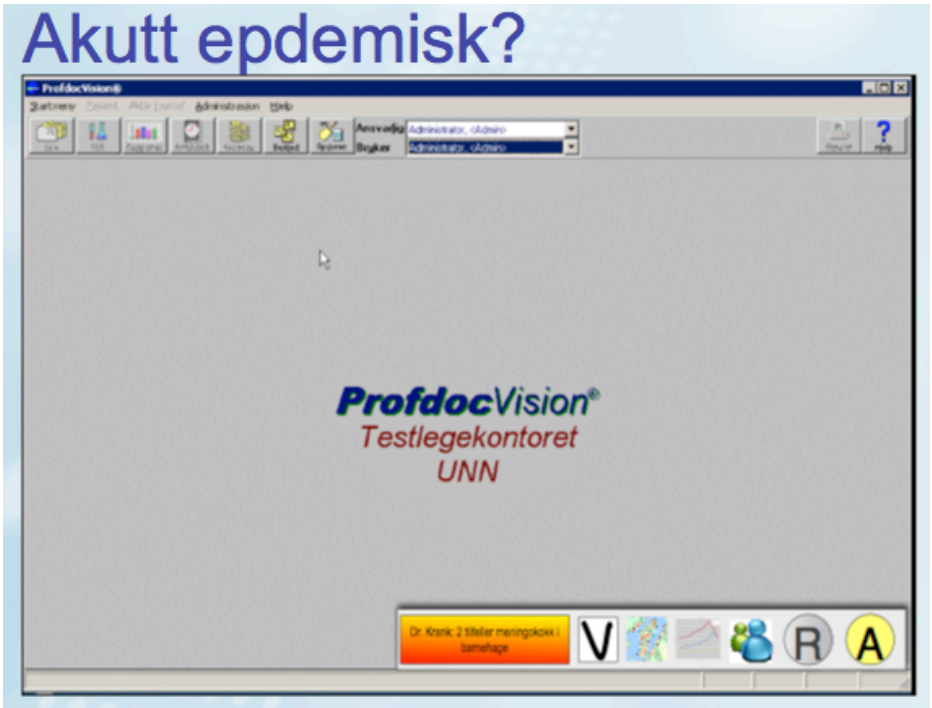


Figure one, showing a symptom based messages poping up.



Figur showing red label message poping up.

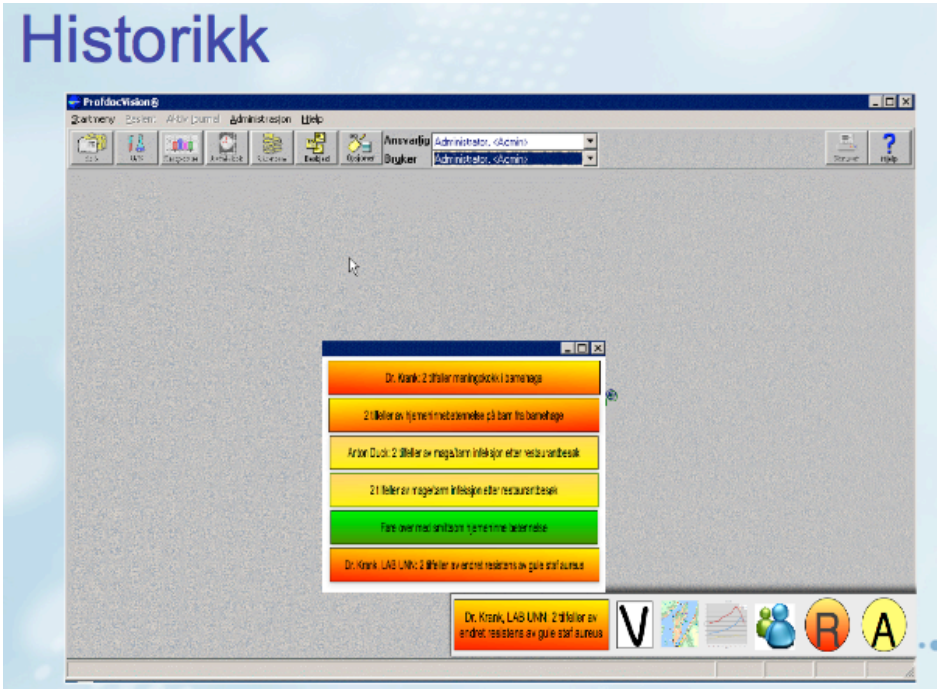


Figure showing history function and green label in additional to an emergency message.

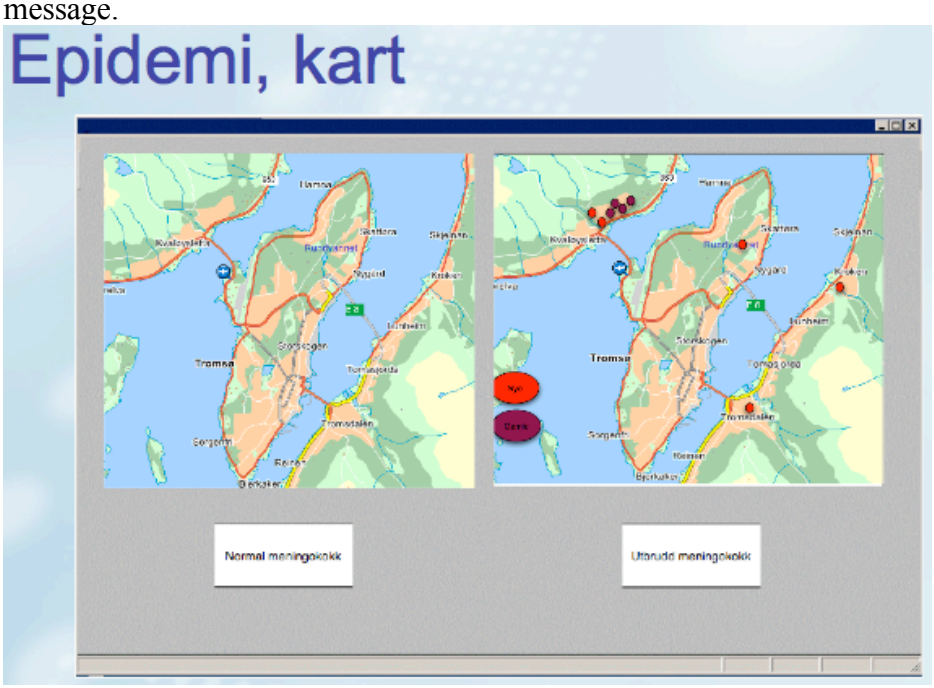


Figure showing map with normal condition on the left and outbreak on the right. Right map show new and previous registrated cases of mengitits.

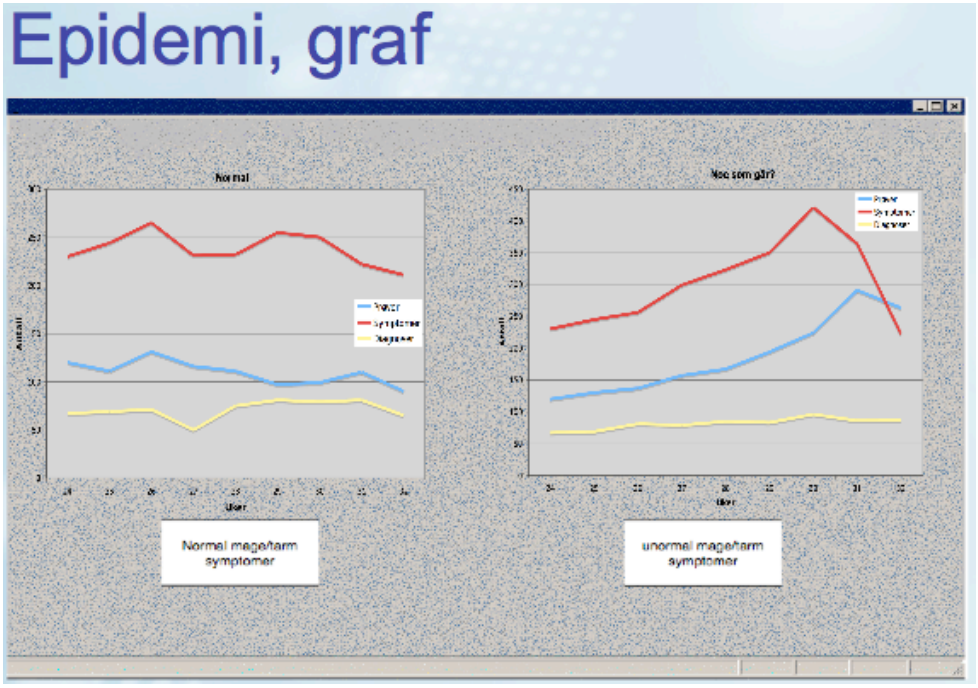


Figure showing chart of normal condition on the left and an outbreak of contagious diseases on the right. Outbreak are symptom based numbers

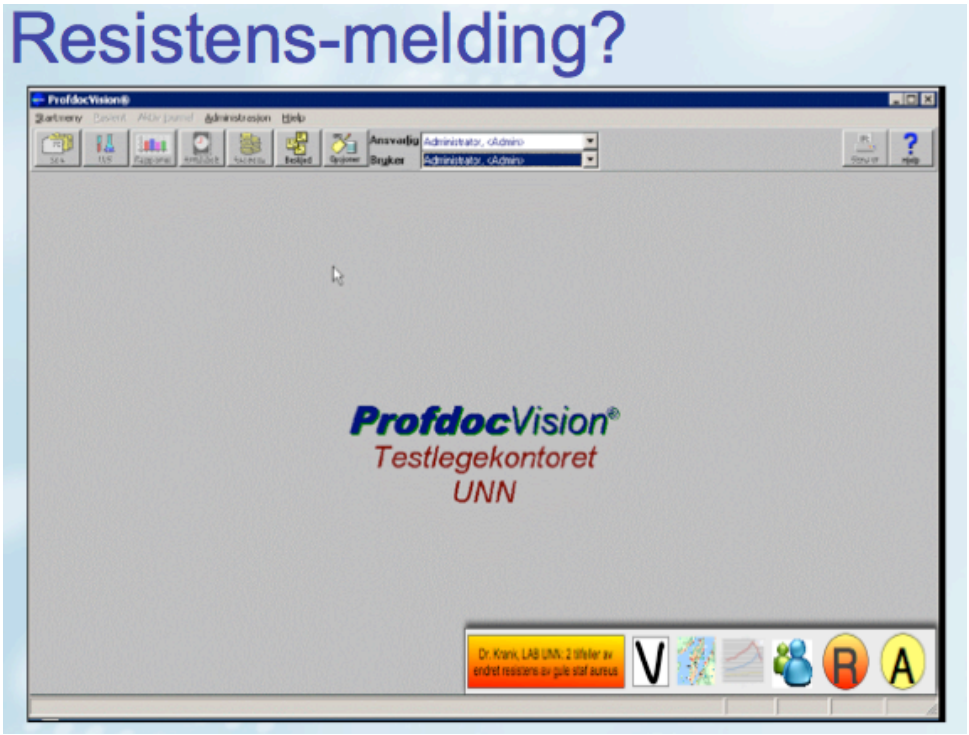


Figure show a emergency message, with highlighted resistance. Since micro organism are identified it is also testet against antibiotic.

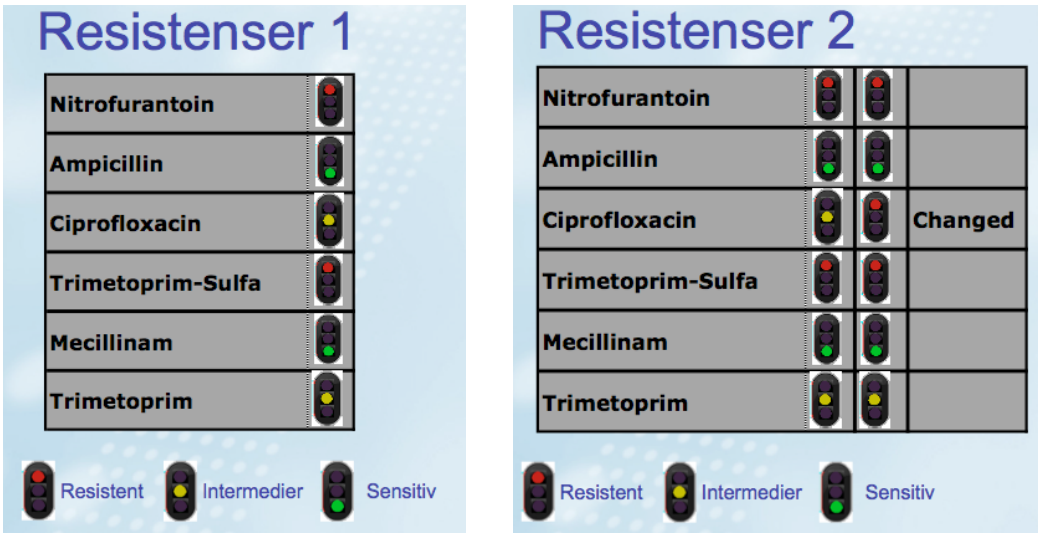
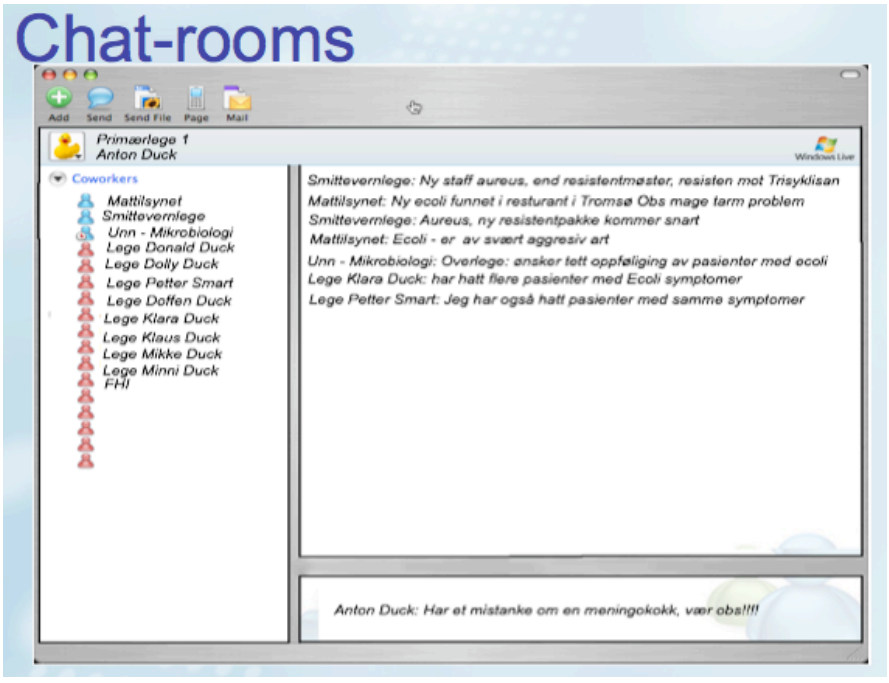


Figure showing resistance panel and results of testing and micro organism against antibiotic. Figure on right mark out which antibiotic the micro organism have been resistensed against.

Figure show an alternativ presentation on phone instead of screen. Left figure shown the message send to the user, with links to map and chart. Figure in the middle show on single map instead of two. Right figure shown chart of symptoms.

Figure showing resitance presented on phone. Both alternativ presented.



Chat room for physicians after an outbreak. An easy way of exchanging message and coordinate information.