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SESSION II: The role of IT in collecting health information

**THE ROLE OF IT IN PROVIDING READY ACCESS TO STATISTICS ON HEALTH CARE
IN DENMARK**

Invited paper submitted by the Ministry of Health, Denmark¹

Summary

This paper focuses on the role of IT in providing ready access to statistics on health care in Denmark.

Firstly the paper describes how data on the use of the health care system is collected on an individual basis. This is possible because every citizen in Denmark has a civil registration number, which is unique to that person. This means that every contact with the health care system is registered, whether it is a visit at a general practitioner, a visit at the hospital or a buy of medicine at the pharmacy. Therefore Denmark has some very large and informative registers on the use of the health care system. The registration numbers are encrypted in the registers but the demands on the level of security are never the less very high.

Next the paper describes the Danish Health Statistical System. The Health Statistical System is a system where data are delivered from the various parts of the health services in Denmark and then made accessible by a distributed client/server solution. For the time being, access to data is

¹ Prepared by Pernille Christensen.

given at three levels. This is necessary because data as mentioned are based on individual registrations. At the most detailed level (Access level 1), only trusted employees are allowed to access data to make analyses and surveys. At Level 2 it is possible, with a security system called SecureID by Security Dynamics, to restrict users of the system only to access certain areas of data. At Access Level 3, the data information is public and can be accessed through the Internet.

All most all data are stored in SAS datasets. At access level 1 data can be accessed trough the SAS System. The SAS System is an integrated system of software providing a complete control of data access, management, analysis and presentation. At access level 2 and 3, data access are given using the internet protocol. This means that data can be accessed using the web-technology.

The HSS is constantly being improved and further developed, and with the implemented security system, it is easy to expand the system so that other user profiles can be granted access to the system.

The role of IT in providing ready access to statistics on health cares in Denmark

This paper focuses on the role of IT in providing ready access to statistics on health care in Denmark.

The Ministry of Health in Denmark has developed a system, which distributes health care statistics on three different access levels. The users of the system are the employees at The Ministry of Health and related institutions, the counties and finally the public.

Before we go into detail with the system it is necessary though to explain how data is collected and why it is necessary to distinguish between the users of the system.

Collecting data:

Denmark is quite unique in the sense that data is collected on an individual basis. This is possible because every citizen in Denmark has a civil registration number, which is unique to that person. To explain how data is collected in the different parts of the health care system lets follow a patients contact with the health care system.

Firstly the patient contacts his general practitioner with a problem.

In Denmark the general practitioners are paid partly on the basis of the number of patients listed and partly on the basis of actual visits made and the specific services the g.p. performs during the visit. The expenses are covered by the patient's home county. This means that for each visit the general practitioner forwards a bill to the county. The bill includes information on the patient's civil registration number, the services performed, the g.p.'s identification number and the date of the visit. The general practitioners that forward the bills electronically to the county receive a special IT-bonus. This bonus is obviously introduced to give the general practitioners incentive to use IT. The result is that approximately 80 percent of the general practitioners transfer the bills electronically today.

The information included in the bill makes it possible to read the following information for every service the g.p. performs:

patient's civil registration number	date	age	sex	patient's county/ municipal	g.p.'s county/ municipal	type of service	the costs	identification number of the g.p.
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During his visit at the g.p. our patient had a blood sample taken. Our patient's visit to the g.p. therefore results in two records: One for each of the two services which the g.p. are paid for, that is the visit and the blood

sample. Our patients visit to the g.p. that particular day will therefore appear in the register as shown²:

patient's civil registration number	date	age	sex	patient's municipal	g.p.'s municipal	type of service	costs	identification number of the g.p.
.....
123456-1234	01011998	50	M	101	101	consultation	160,55	1234
123456-1234	01011998	50	M	101	101	blood sample	38,82	1234
.....
.....

All data are sent from the counties to a central database on a monthly basis. The database contains approximately 72 million records per year. This means that each citizen in Denmark on the average are found 14 times in the register per year.

The register on the use of general practitioners is therefore generated on administrative data and does not include information on diagnosis. The register dates back to 1990.

Lets look at our patient again. At the g.p. he got a prescription for some medicine, so he walks to the pharmacy.

In Denmark medicine which is only dispensed on prescription is subsidized. The subsidy is paid by the patient's home county. This means that for each package of medicine which the pharmacy sells on prescription it registers the patient's civil registration number, the code number of the medicine, the identification number of the g.p. who wrote the prescription, the date etc. This information is then forwarded to The Danish Medicines Agency on diskettes each month. Hereby it possible to read the following information for each package of medicine sold on prescription:

patient's civil registration number	date	age	sex	patient's county/municipal	g.p.'s county/municipal	identificat ion of the g.p.	the atc-code	number of packages	costs
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Our patient will then appear in the register with this particular buy of medicine in the following way¹:

² All data shown is fictitious. The register contains several other variables.

patient's civil registration number	date	age	sex	patient's county/municipal	g.p.'s county/municipal	identification of the g.p.	the atc-code	number of packages	costs
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..... 123456-1234 01011998 50 ..	. M 101 101 1234 B01AA03 1 150,00
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The register on the use of medicine is therefore also generated on administrative data. The register dates back to 1994.

Back to our patient who unfortunately forgets to take his medicine. He gets really sick and is admitted to hospital.

At the hospital information on the patient is registered in the local administrative system. The local administrative systems differ between hospitals, but The National Board of Health has in cooperation with the counties, who run the hospitals, defined a set of records that every hospital must register. When the patient is discharged from hospital the record is closed and the information is transmitted to the National Board of Health on a monthly basis.

For each patient discharged from hospital the following information is forwarded to the central database¹:

patient's civil registration number	date of admission	date of discharge	age	sex	hospital number	patient's county/municipal	diagnosis	(potential) operation code	length of stay
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In this case our patient will appear in the register with one record in the following way:

patient's civil registration number	date of admission	date of discharge	age	sex	hospital number	patient's county/municipal	diagnosis	(potential) operation code	length of stay
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..... 123456-1234 28011998 01021998 50 M 1301 101 I740 4
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The register on the use of hospital services is generated on a mix of administrative and clinical data. The database on inpatients contains approximately 1 million records per year and the register dates back to 1977.

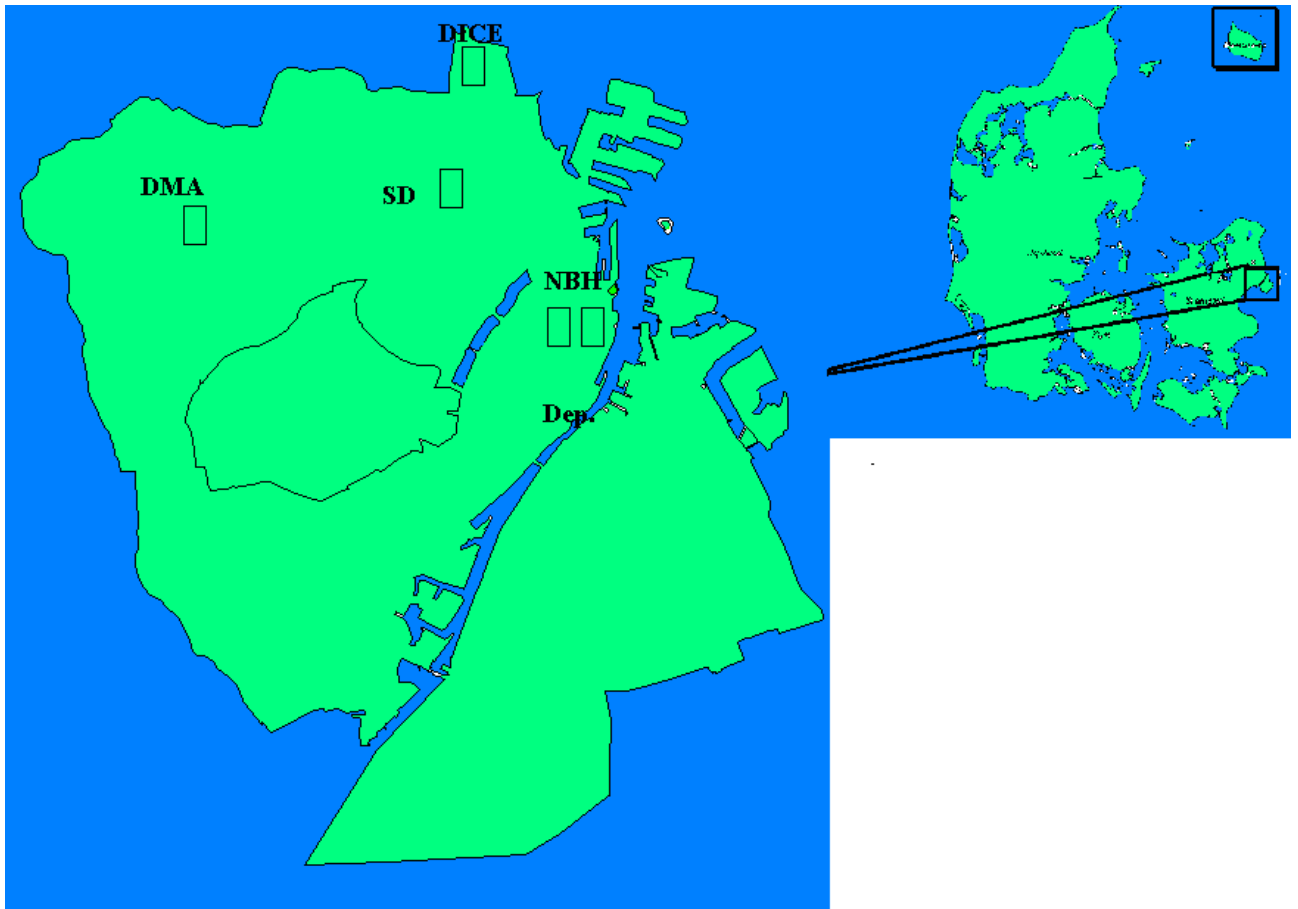
The three mentioned registers are kept by The National Board of Health and by The Danish Medicines Agency. Data is received from the counties or hospitals as described but the civil registration numbers and the general practitioners identification numbers are encrypted before the registers are made accessible. Very few persons have access to the original data.

Storage of data:

Before we describe how data are kept we need to explain the organisation of the Ministry of Health in Denmark. The Ministry of Health consists of The Department (Dep.), The National Board of Health (NBH), The Danish Medicines Agency (DMA) and a few other institutions. Furthermore exists The Danish Institute for Clinical Epidemiology (DICE) as an self-governing institution under The Ministry of Health.

As described above the National Board of Health keeps the register on the use of hospital services and the register on the use of primary health care services while the Danish Medicines Agency keeps the register on the use of medicine. Each register is kept on a UNIX-machine situated at the institution. In addition to the above mentioned registers several other registers exist including survey data on the populations health status which is collected by The Danish Institute for Clinical Epidemiology.

To illustrate where the data are kept physically the location of the institutions in Copenhagen is shown on the map of Copenhagen below. Included is Statistics Denmark (SD) with whom The Ministry of Health exchanges data. As shown data are stored on five UNIX-machines: One at DMA, one at DICE, one at SD and two at NBH.



This system only makes it possible for an employee at one institution to access data located at the same institution. It has however been desired that employees at all institutions including the Ministry's Department could access the registers in the encrypted versions. It has furthermore been desired to give the counties access to data on their own citizens' use of the health care system. Finally it has been desired to give the public access to data on an aggregated level.

This means that it has been necessary to build a system which gives access to data on three different levels. The rest of the paper will describe how this system has been build.

The Technical Solution behind the Health Statistic System.

In this section, an overview of the technical solution behind the Health Statistic System (HSS) is given. First, there is a short description of the hardware and software used in the HSS. Secondly, the level of accessibility of data is described which depends on the user's professional relations with the health services. Thirdly, it is described in detail how data can be accessed.

The Hardware

The HSS is built as a distributed client/server solution. On the server side, the machine types are UNIX and NT. Depending on the clients' physical location, they connect to the servers through a local area network, an intranet or the Internet.

The Software

To store and maintain, retrieve and administrate data, a single software-product is used, i.e. the SAS System, developed by SAS Institute Inc. The SAS System is an integrated system of software providing a complete control of data access, management, analysis and presentation.

At the Ministry of Health, a number of front-end applications have been developed (in a the SAS programming language) in order to operate on the huge amount of data available, e.g.:

- a datawarehouse built to maintain the HSS
- special applications for fast retrieval of standard reports
- application for dynamic creations of WebPages with data access facilities

Accessing Data

As mentioned, data are based on individual registrations and can be misused. Consequently, the priority of security concerning the access of data is very high. Depending on a user's professional relations in the health services, access to data is given at various levels. For the moment, the levelling of accessibility of data can roughly be divided into three access levels.

Access Level 1:

The Ministry of Health including
The National Board of Health
DICE
The Danish Medicines Agency

Access Level 2

The health authorities in the various counties

Access Level 3

The public

The first level includes authorized employees employed directly in the Ministry of Health. These employees are allowed to work with data at the most detailed level.

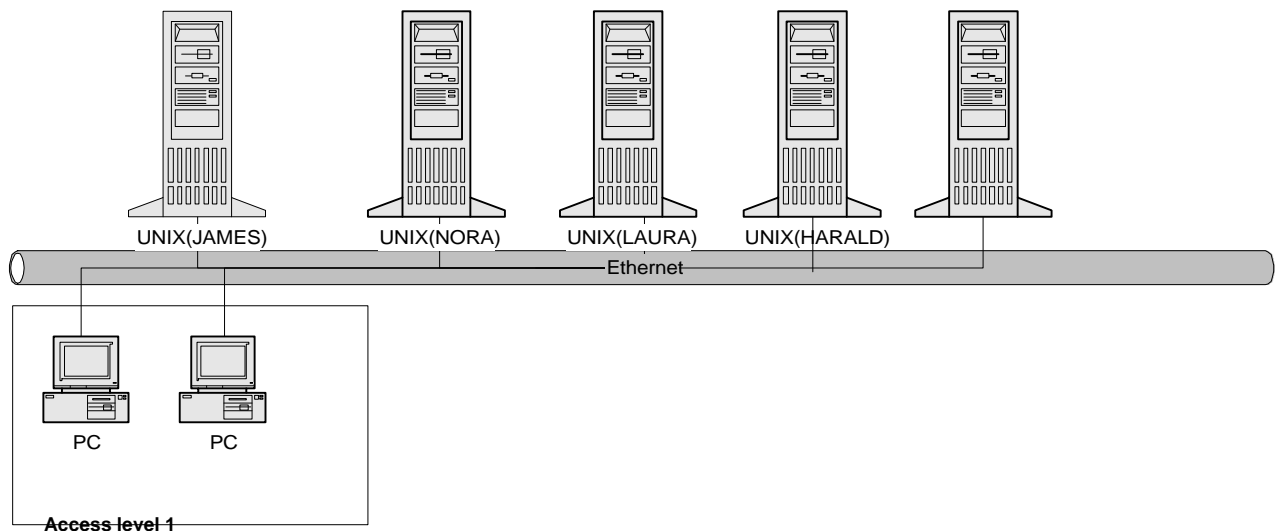
At the second level, data access is given to the health authorities in the counties of Denmark. There are 16 counties in Denmark, and in each county about 4-5 people are allowed to work on data related to that specific county. If agreements on data access between the counties are made, it is also possible to work on data related to other counties.

At the third level, data access is given to the public, e.g. students, journalists and others with interest in health statistical information. At this level, health-related information is made accessible through the Internet. The data accessible through the Internet are summarised data, and consequently there is no restriction on the users allowed to work on these data.

In the next section, it is described how the HHS is built so that it can handle requests from different kinds of user profiles and only give access to relevant and permitted data areas.

Access Level 1 - Employees in the Ministry of Health

As mentioned, access at this level is given to authorised employees, directly employed in the Ministry of Health.



In order to connect to the system, the user must first login to the local area network at the Ministry of Health. The illustration shows how PC's and the UNIX machines are connected via and TCP/IP-based Ethernet. Remember that data are stored at the responsible institutions. The UNIX machines are connected to the HSS with 2Mb data lines.

From the network, the UNIX-servers can be reached through the SAS/CONNECT³ and a SAS login-shell. Within this access level there is also some differentiation between the users, and consequently the second login is required.

If a user has the right to connect to a UNIX-machine called NORA where the data on the purchase of medicine is stored, the user can issue a signon from the SAS System.

After a correct userid and password, data-access is now possible either through the front-end applications or directly by the SAS programming language and SAS-SQL.

(short demonstration on the access of data at this level)

Access Level 2 - The Health Authorities in the Various Counties

Recently, it has been made possible for the counties to access health statistics directly through the HSS. The health authorities in the counties are connected to the HSS via ISDN-lines.

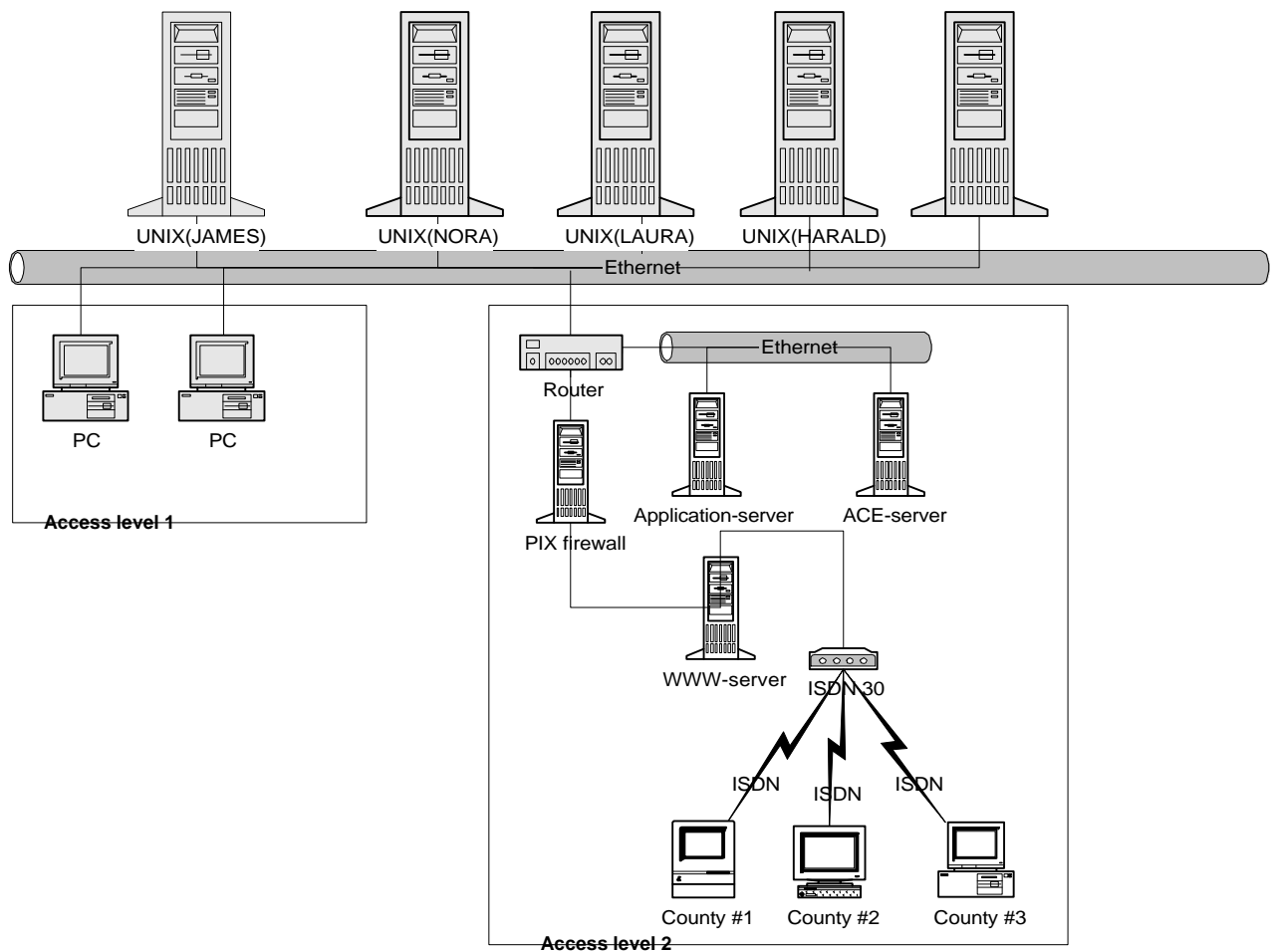
To avoid having to maintain thick clients, the retrieval of health-statistics and information are based on the internet protocol. In this way, data can be accessed directly through a web-browser.

As mentioned above, the health authorities are - in some data areas - only allowed to see data related to their own county. To ensure this, a security system has been built. The security system is based on a product called SecurID⁴ by Security Dynamics. In order to login to the HSS, a username, a token card providing a password, and a pincode are necessary. In this way, the access to data relies on something the user must own, the token card, and something the user must know, the pincode.

Below the essence of the intranet in the HSS is illustrated. It is the second access level of the HSS.

³ For more information on the SAS System and SAS/CONNECT please see:
<http://www.sas.com/software/components/connect.html>

⁴ For more information on the SecurID please see:
<http://www.securitydynamics.com/>



Again, the SAS System is used to implement the client/server solution on the software side. A SAS module called the SAS/IntrNet is used. The SAS/IntrNet makes the use of the SAS System available to the Web without having SAS installed on the client-computer. This is why access to data can only be made using a webbrowser.

The SAS/IntrNet includes many features such as Java programming tools, Warehouse-viewer for the Web, VRML, graph animation, etc. To build the second access level in the HSS, a tool called the Application Dispatcher is used which is also included in the SAS/IntrNet module. Below it is described in detail how the Application Dispatcher works.

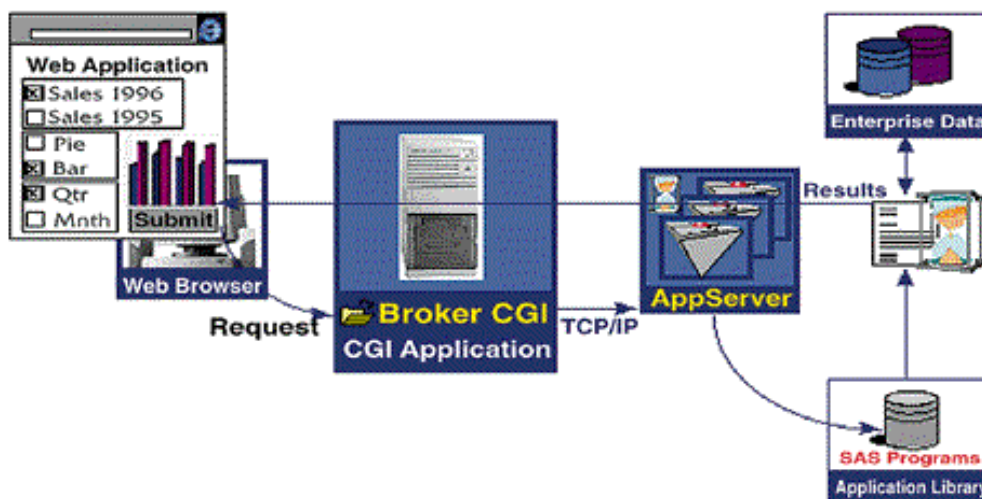
From a webbrowser the user fills out some fields in an HTML form and submits it. The information from the form is passed on to the Ministry of Health's Web server which invokes the first component of the Dispatcher called the **Application Broker**.

The Broker retrieves the data and sends it to the second Dispatcher component, called the **Application Server**, which runs on the Application server machine. Information passed to the Broker tells the Broker which Server-process should process the request.

The Application Server invokes a SAS program that processes the information. This is where the real power of the system comes into play. The SAS-programs access data stored on the Application server machine or on the UNIX machines.

The results of the program are streamed through the Broker to the browser and the waiting user.
Any necessary cleanup is done.

The entire process can be completed in as little as one second, depending on the speed of the machines involved. The following diagram, illustrates how a communication request is submitted and processed.

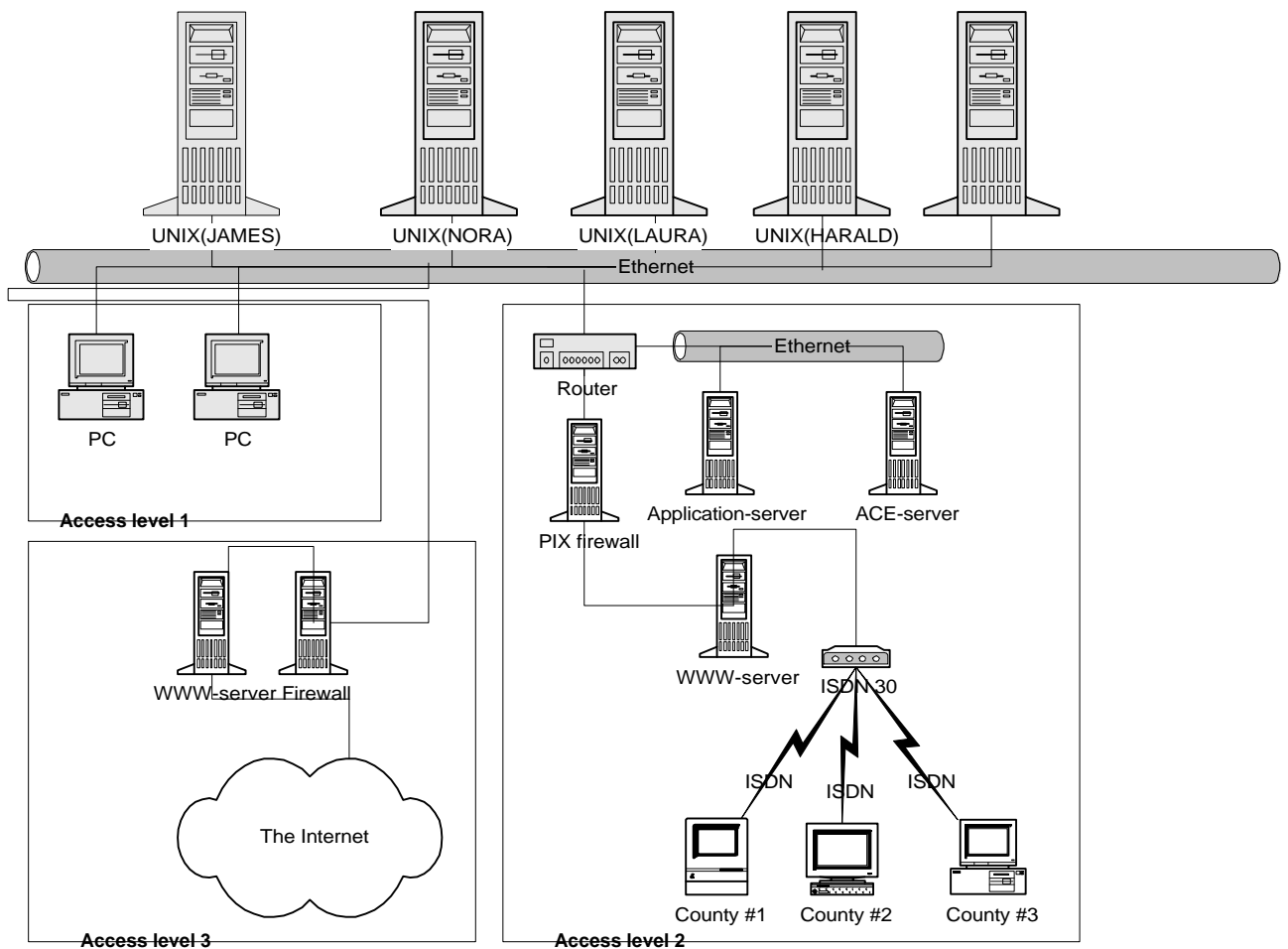


Furthermore, as the SAS System is used in some of the counties in Denmark, it will also be possible in the near future to connect to the HSS through SAS using the SAS/CONNECT module.

Access Level 3 - Health Statistics to the Public

The third access level is where access is given to the public through the Internet. Health-related information is made accessible through the Internet. The data accessible through the Internet are summarized data, and there is therefore no restriction on the users allowed to work on these data.

The way data are accessed is similar to that described for the second level. The difference lies in the data available and the security. Data are summarized and everybody is allowed to view the content. Consequently, there is no need for a security layer besides a firewall to the LAN. Below the third access level connected to the HSS is illustrated.



The illustration stated above shows how the HSS looks today including all three levels of access.

Access Level Summary

To make a short summary of the access levels, the keypoints at each level can be listed as follows:

Access level 1:

Employees employed directly in the Ministry of Health
Data can be accessed to the most detailed level through SAS/Connect
Special analyses and major surveys are based on the data.

Access level 2:

Health authorities in the various counties
Access to data related to the county can be obtained at a very detailed level
Data are accessed through SAS/IntrNet.
Data will be accessible through SAS/Connect in the future.

Access level 3:

Public access to health statistical material
Users can retrieve data from summarized dataset
Data are accessed through SAS/IntrNet.

It is important to note that no matter on which level data are accessed, it is always the latest update which is available. Some requests from the system are made directly on the original, stored data while others are made on subsets created by a scheduler routine so that the subsets are created in the moment the real datasets are updated.

To conclude, the Health Statistical System is a system where data are delivered from the various parts of the health services in Denmark and then made accessible by a distributed client/server solution. For the time being, access to data is given at three levels. This is necessary because data are based on individual registrations. At the most detailed level (1), only trusted employees are allowed to access data to make analyses and surveys. At Level 2 it is possible, with the SecureID facility, to restrict users of the system only to access certain areas of data. At Access Level 3, the data information is public and can be accessed through the Internet.

The HSS is constantly being improved and further developed, and with the implemented security system, it is easy to expand the system so that other user profiles can be granted access to the system.