MAPPING THE HEALTHCARE DATA LANDSCAPE IN DENMARK

Report

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About this report

This report is prepared by Leapcraft ApS on request by Copenhagen Healthtech Cluster, Copenhagen Capacity in May 2015.

The premise of research has mainly been intensive desk research done over 8 weeks and a combination of Leapcraft’s experiences on working with big data solutions for the Danish market. We have tried to ensure that the list of medical databases referred to and listed in this report are still active and that the list itself is exhaustive. However it is not a comprehensive or complete list by any means.

Wherever possible and relevant, statements about institutions and organisations have been borrowed from their own website to ensure the correct interpretation of their role and activities.

DISCLAIMER: All material presented in the report is meant to be indicative and to inform Copenhagen Healthtech Cluster’s research needs. This report is not for public use or research purpose.
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1. Introduction

This report aims to understand the known sources of healthcare data in Denmark and see how this data is connected and can be correlated to each other and other social data to make it meaningful to more stakeholders in the healthcare sector, the healthcare industry of diagnostics, medical devices, private healthcare and insurance and of course, to citizens themselves. The report also outlines the legislative and ethical guidelines around usage of health data in Denmark through scenarios of use to highlight challenges in information exchange at intra- and inter-sectoral levels.

Beginning with a comprehensive layout of the Danish social welfare system which is the primary link between the citizen and state and thus a robust database, the report in chapter 2 introduces all the public sector players who collect, collate and use health data. Points of contact and interaction in the system that generate this data have been discussed in detail along with possibilities for citizen access to both personal and public data. A short overview of the procedures around retrieval and use of data for research access as well as commercial use (including research for commercial pursuits) is presented. While the registrations are intensive and often exhaustive, the formats themselves are not aligned and hence this chapter delves deeper into the issues of data integration and discusses in further detail the registration practices, even at the most basic patient - doctor level, that essentially generates this data. This analysis helps outline the barriers and challenges in the health data landscape as it is now, and can help in improving the framework for future databases.

Chapter 3 discusses in further detail the various categories under which this healthcare data is collected describing the periods of time and population breadth covered in these, thus reflecting on the quality of the available data. The various registers are classified in detail here covering clinical data registers, quality indicator registers and tissues and bio materials sample databases.

Privacy around personal data is given great importance in Denmark, giving great credibility to health data generated here. Chapter 4 lists the various agencies that work towards keeping this system secure in good detail giving one an overview of the legal framework for potential cross sectoral research projects and further data mining. The challenges to accessing information stored in specific registers at both intra- and inter-sectoral levels has been outlined.

Chapter 5 looks at possibilities to synthesise the various data sources and make new sense from it. After mapping existing efforts, the report looks at potential new lenses to see the same data like demography, general wellbeing and chronic illnesses. An attempt has been made to see the entire landscape of data sources mapped on a lifetime. As we see this historical data collection activity as a mass of data on specific factors, it reveals evolution of lifestyle syndromes, focus of the healthcare sector and policy making, gender based tendencies etc. Analysis can take take a predictive turn as the map can be interpreted across many indicators.

Using the body as a spatial metaphor in chapter 6, the various registers are mapped giving one an overview of areas of keen research interest, funding and of value to population studies. All kinds of registers are notably mapped here, stressing the volume of data that exist for a particular area of study.

A detailed contextual extrapolation of data use is explained in chapter 7 citing potential use case scenarios and the way forward to realise these mentioning the different stakeholders and a possible road map.

The report concludes with a road map for use of this healthcare data combined with other rich socio-economic data collected in Denmark for welfare projects and private sector projects.
1.1 Background

The Nordic countries have been front runners in the collection of data on births, deaths, disease and its control. Data on education and employment, immigration and emigration have also been duly collected as it was and is the backbone of the welfare state model. Growing population, tax collection and disbursement of complex welfare funds pushed the state’s early foray into digitisation of data. Thus very high quality data of the whole society is available for varying, yet long periods of time.

For example, information on causes of death has been collected since 1875 in Denmark, information on compulsory schooling and continuing education are available for cohorts born after 1945, information on twins are available for cohorts born after 1870, and cancer incidence has been registered for the whole country since 1943.

5 CPR- Det Centrale Personregister https://cpr.dk/
7 CVR- Det Centrale Virksomhederegister http://datacvr.vir.dk/data/

1.2 Identity as a National Infrastructure

Using a unique personal identification number assigned to all persons with a permanent residence in Denmark (CPR-number), it is possible to link data from one or more registers or from other sources with register-based information at an individual level. It was established in 1968 and contains the name, address, personal identification number, date and place of birth, citizenship and other information about the country’s citizens and residents.

Additionally, each Danish firm has a unique identification number, the CVR Number, which makes the link between a firm and employees possible. Thus, the access to information on important exposures, confounders such as education, income, and ethnicity and various health-related outcomes offers immense opportunities for doing epidemiological research on, for example, the association between occupational exposures, disease incidence, mortality, social issues, clinical indicators, and rehabilitation.

Additionally, all data pertaining to real estate properties in Denmark are maintained in the BBR which includes detailed historical data on property evaluation, condition, renovation, ownership and pollution levels of constructions. This in-depth recording reflects socio-economic data that can be related to population transition, lifestyle and well being.
2. The Landscape of Danish Healthcare

The layout of the Danish healthcare system and the Danish political system forms an important basis for the work on eHealth in Denmark. Health care in Denmark is based on two main principles:

*Free and equal access to public health care.* This includes general and specialised practitioner services and services at all public hospitals. Dentists and out-of-hospital medicines and some therapies are provided under private or co-payment models on a case basis.

*Universal coverage.* All residents in Denmark are entitled to public health care benefits in kind.

The public health care system is organised in two main sectors: primary health care and the hospital sector. The primary health care sector deals with general health problems and care and consists primarily of general practitioners, practising specialists, practising dentists, physiotherapists and home nursing. Primary health care also includes preventive health schemes, public health care and dental care for children.

The hospital sector deals with medical conditions that require specialised treatment, equipment and intensive care. A general practitioner (GP) must refer the patient to a hospital for examination and treatment unless it is a question of an accident or acute illness. Usually it is necessary to be referred by a GP for treatment by a specialist. Since 1993, patients have had the right to choose between all public somatic hospitals for treatment. An extended free choice, since 2002, has given patients the right to choose a state financed treatment at a private hospital if waiting times at the public hospitals are too long.

The administrative break up of the between:
1. The State
2. Danish Regions (Danske Regioner)
3. Municipalities (Kommune)

The Sundhedsdatastyrelsen, part of the Sundheds- og Ældreministeriet is the agency for the National Sundhed IT (NSI) that until August 2015 was part of the Statens Serum Institute.

2.1 The State

The CPR and CVR registers along with property data recorded in the BBR are nationwide registers pertaining to all citizens and residents of Denmark and established protocols means the extrapolation of all this data with a single identification number is possible, but not explicitly done today. The data is informative and forms the basis of nearly all register based researches in the country. The data is gathered and accessible nation wide and a large part of this (except the CPR number itself) is available for research and commercial use and further, the anonymisation of data, partly or wholly is possible. Aggregated data and statistics from these registers is made public.

2.1.1 Danish Regions

The Danish Regions coordinates the common interests of the 5 regions at the national level and negotiate the annual financial framework for the regions with the government as well as enter into agreements with the private practising sector including GPs and dentists. Public hospitals and contracts with all GPs are the undertaking of Danish Regions (Danske Regioner). The data collected is currently from the primary healthcare and the hospital sector which use different platforms and registration protocols. Yet, the data collected is almost entirely digitised thus generating an intense, deep pool of e-health records pertaining to every individual’s healthcare history. While the data can be transferred across systems, the format is still text documents. The Regional eHealth Organisation (Regionernes Sundheds-IT organisation – RSI, est. 2010) accelerates and coordinates the implementation of eHealth across the five regions. All projects, collection of data and maintenance of databases are carried out with one of the regions as the main principal.

2.1.2 Municipalities

The regions are divided into 98 municipalities (Kommuner) and are responsible for a wide range of health services like local and specialised dental care and rehabilitation preventive treatment, homecare, nursing homes, rehabilitation (not hospital), treatment of alcohol and drug abuse, social psychiatry and physiotherapy. Thus the municipalities collect data on various socio-economic indicators giving deep insights into every individual where therapy and chronic care at the municipality level can thus be linked to various other municipality activities such as education, work place conditions, tax collection, welfare schemes.
Illustration 1: The Landscape of Danish Health Care - Infrastructure & Access

The nationwide infrastructure is continuously recording personal data at the state (geo-bio data), region (e-health records) and municipality levels (e-care records). The data, specifically, healthcare data is recorded in national registers, tissues and samples are collected in bio banks and data of specific health conditions is actively recorded in clinical databases, by active participation and inactively by course of treatment in hospitals.

Access to the data is made available both for personal use (one’s own data) and is systematically anonymised at various resolutions for research purposes. This infrastructural landscape is well integrated ensuring every instance of interaction between the state and the resident is documented both qualitatively and quantitatively.

2.2 Data Infrastructure

All the health databases are administered by a data manager who works within the Regions Competence Center. Data entry for some databases is directly done into the nationwide register, while some others are maintained in regional registers which in turn plug into the nation wide register. There is double documentation of some variables in this case.

Competence centers have been established in all the 5 regions and they oversee the IT requirements of each database, identify relevant clinical content, workflows, IT advice and offer data analysis validated by statistical epidemiological principles. There are 3 competence centers for register based Epidemiology Studies while the other 2 are focussed on data quality and indicators.

Kompetencecentre for Epidemiologi & Biostatistik (KCEB)
KCEB-Nord – Located in Aarhus/Aalborg
KCEB-Syd – Located in Odense Universitetshospital
KCEB-Øst – Located in Glostrup as a part of the Forskningscenter for Forebyggelse og Sundhed (Research center for Prevention and health)

Kompetencecentre for Klinisk Kvalitet & Sundhedsinformatic (KCKS)
KCKS-Vest – Located in Århus, along with RKKP
KCKS-Øst – located in København Ø, as part of IT, Medico og Telefon, Region Hovedstaden

The Danish Healthcare Quality Programme (Den Danske Kvalitetsmodel, DDKM) is a national accreditation system for quality development across the entire healthcare sector along with methods to measure and control this quality. The programme serves as a method to produce continuous and persistent quality development across the entire healthcare sector. The DDKM aims to generate and combine data which is already being collected in the Danish healthcare sector. This data includes, among other things, the national quality databases, data on adverse events, national patient satisfaction surveys. DDKM is public and multisectoral.

The Danish Institute for Quality and Accreditation in Healthcare (Institut for Kvalitet og Akkreditering i Sundhedsvesenet) IKAS develops, plans and manages the DDKM.

2.3 Data Administrators

The Regions’ Clinical Quality Development Programme (Regionernes kliniske Kvalitetsudvikling Program, RKKP) represents infrastructure supported nation wide clinical databases, Danish multidisciplinary Cancer Groups (DMCG) and centers of epidemiology, biostatistics, health informatics and clinical quality. The program’s primary objective is to ensure continued improved utilisation of the nationwide clinical databases. It was formed in Sept. 2010 and has since focused on ensuring the framework for prioritisation and management of databases; better use of existing data / reduction of data entry tasks; standardisation of inputs and outputs in relation to databases; product development and proper method development. The RKKP is located in Århus. The five regions have their own competence centers for clinical epidemiology and they work together with the Joint Secretariat (the RKKP).

2.3.1 Documentation- General Practitioners (GP)

In Denmark around 98% of the population (health insurance group 1) are assigned to a specific general practitioner through a list system. The GP acts as a gate-keeper with regard to referrals to specialists and hospitals, and services are free of charge. The remaining 2% of the population (health insurance group 2) have chosen the right to consult any GP or practising specialist at any time, in return for paying a substantial part of the doctor’s fee. Services to both groups are registered in the National Health Service Register (NHSR).

The data in the register is generated through the GP’s invoices to the Regional Health Administration. All practices are computerised and they send an electronic fee request containing information about the citizens, the provider, and the type of service to...
Illustration 2: The Danish Healthcare Landscape: What data is collected? Who has health data? Who can access it?

Here, it can be seen that the state itself is actively involved in cross sectoral data analysis that it presents through various platforms both at the individual level (Statens Institut for Folkesundhed) and nation wide level (Danmarks Statistik). The data collected and managed by various agencies reflects their focus and in turn the various kinds of research projects the data feeds into. The data owners work under larger universities (for domain knowledge), as national infrastructure (regions, municipalities) and independently (Statens Serum Institute, National Biobank). Data is accessible at various resolutions depending on the need for access (fundamental research, industry assisted research, self health monitoring, nation-wide health and wellness trend monitoring etc.).

However it appears, that a holistic overview of all of a person’s personal data is perhaps visible only to the State through the CPR number. While the linking all the various data silos is technically possible, there are no platforms that offer this linked socio-economic-health view to the individual.

At a higher demographic level, population data will need to be parsed quite extensively to collect similar parameters for comparative studies across specific population studies. The nature of data, both raw and collated that is readily available for commercial research remains however unclear.
The Regional Health Administration every week which passes the information on to the National Board of Health (Sundhedsstyrelsen). The list of variables is comprehensive.22

The GPs occupy a central position in the Danish health care system as the patients’ primary point of entry to health services. The GP ensures that the patient is given the right to treatment and right treatment and is referred to the right professionals in the health service. The GP is thus the coordinator and the person with professional responsibility for referring patients to hospitals, specialists and other healthcare professionals.

2.3.2 Who generates what type of data?

Every point of contact with the health care system generates information and data about a patient. This can be both quantitative and qualitative and registers are maintained to that. Some of this data is of primary nature (raw data) and the rest is secondary data that is derived from the registers or reflecting registers.

In the Danish context, most of the healthcare is managed by the public healthcare system, and yet a small fraction is supplemented by the private healthcare who are still obliged to maintain the personal heath records of the patient during the period of treatment at a private center. Examples of data generated are provided in the table below. For further reading refer Sec.3 on Pg 13

Table 1: Who generates what type of data?

<table>
<thead>
<tr>
<th>PRIMARY DATA</th>
<th>EXAMPLES OF QUALITATIVE CONTENT</th>
<th>EXAMPLES OF QUANTITATIVE CONTENT</th>
<th>RESPONSIBILITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Practice records</td>
<td>Observations, symptoms, diagnosis, medical history, prescriptions, requisition of tests.</td>
<td>Vital statistics, test results, Frequency of visits, Total time per case.</td>
<td>GPs</td>
</tr>
<tr>
<td>Pharmacy records</td>
<td>Prescription, Compliance, Drug Interactions, Allergies.</td>
<td>Waiting time, Frequency of order, Population health.</td>
<td>Pharmacies, Hospitals</td>
</tr>
<tr>
<td>Electronic Care Records</td>
<td>Summary of point of care, Patient Satisfaction, Record of incomplete care.</td>
<td>Use of resources, Personnel, time, infrastructure etc., Treatments, Tests if any.</td>
<td>Visiting health professionals, GP, Rehabilitation</td>
</tr>
<tr>
<td>Electronic Health Records</td>
<td>Diagnoses, treatment, imaging.</td>
<td>Pathology, lab results, Outcomes, Treatments, Tests if any.</td>
<td>Hospitals</td>
</tr>
<tr>
<td>Health Insurance Records</td>
<td>Treatment, outcomes.</td>
<td>Costs, resource use.</td>
<td>Private or Public health insurance</td>
</tr>
<tr>
<td>Biological samples</td>
<td></td>
<td>Material profiles, patient profile.</td>
<td>Bio-banks, Hospitals</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SECONDARY DATA</th>
<th>EXAMPLES OF QUALITATIVE CONTENT</th>
<th>EXAMPLES OF QUANTITATIVE CONTENT</th>
<th>RESPONSIBILITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health registers</td>
<td>Patient profiles.</td>
<td>Costs, resources.</td>
<td>Individual register owners</td>
</tr>
<tr>
<td>Patient communities (e.g Diabetes, Cancer, psoriasis, alcohol rehab etc.)</td>
<td>Patient profiles, compliance, preferences, support.</td>
<td>Costs, resources, Treatment efficacy.</td>
<td>Community managers</td>
</tr>
</tbody>
</table>

2.3.3 Types of Documentation

All data generated and collected can be broadly classified under the following types. While some of them are qualitative, some others are quantitative and the format can be both text (.xml) and numerical values.

**Patient behaviour**
Health issue, compliance with treatment, outcomes, personal choices or preferences

**Health outcomes**
Medical records, hospital statistics, insurance data, observational indicators

**Longitudinal Patient records**
Pathology, drug and product information, social and environmental factors, medical history consisting of diagnosis codes, doctor’s notes, lab reports and diagnostic images - wounds, x-rays etc.)

**Resource Use**
Each contact with the health care system (time waited, spent and quality), treatments, costs etc.

**Population Health**
All clinical data generated under controlled randomised trials, other structured content like lab tests, images or unstructured content like notes, medical history etc.

**Monitoring devices**
At home monitoring devices, personal devices, apps that quantify the body or physiological data generated from bedside monitors at hospitals and other sensors.

**Sales & Marketing**
Data from pharmacies, sales, marketing and product data, insurance claims etc.

**Other reflecting data**
Environmental data like weather, pollution, atmospheric allergents, disease outbreaks etc.

2.3.4 Registration Practices

Typically, entering data to the central registers is handled by secretaries who report the interaction between the doctor and the patient. The reporting of data from hospitals to the central records is ongoing in the patient administration systems (PAS) systems.

*For further reading refer Sec. 4.7 on Pg 24.*

The decision on who is responsible for registering the quality databases is taken at the branch level. This means that it varies from department to department, on whether the registrations are made by a clinician, a nurse or a secretary. However, in most cases, doctors or nurses in charge of the case inputs to quality databases.23

The input of data to the central registers typically happens as follows:

1) The doctor collects information as part of a conversation with the patient, or an operative procedure and writes notes, fills out forms or dictates notes to the secretaries.
2) The information is thus transferred to the secretaries who in turn input the information in the patient administrative system and edit or debug the entries.

Input of data to the clinical quality databases are

1) The doctor inputs the information - but rarely as the collection of information happens (i.e not during a patient visit or procedure)
2) The nurse inputs the data
3) The doctor fills out a form which is then input by the secretary. The most common of course the first two options and a conservative estimate is that 2/3rd of all information input happens this way.24

Recording practices in clinical quality databases can be generally categorised into three main groups.

1) The recording is directly done into the other central registers (LPR, pathology register, etc.) and thus there are no independent records in the database.
2) The recording reports directly to their own database. The same information is reported in varying degrees to both the central registers and database causing double registrations.
3) Combination of shared recording with central, and separate reports.

23 http://www.sum.dk/Aktuelt/Publikationer/Analyse-af-kvalitetsoplysninger-i-Danmark-juni-2010/Kapitel%204.aspx
24 ibid.
Illustration 3 Platforms, Flow of Messages and Quality of Data between the various stakeholders.

All messages between the different stakeholders and sectors (primary & secondary) are marked in this flow chart of electronic messages.

The administrators (municipality) and online interfaces (sundhed.dk) are also marked here as a source of generating and receiving messages. The digitalisation strategy in the public sector of Denmark has intended to reduce person based interactions (enquiry, reporting etc.) and paper work (intimations, collection, imposing of fines etc.) to a bare minimum by creating a single online interface for this. Here, one sees only the health sector, but a similar messaging protocol exists in other public sectors as well.

The nature of the messages are both qualitative (text, like surveys, journals, notifications, reports) and quantitative (numerical, like pathology reports, biological profiles etc.). Numerous databases on quality of healthcare are maintained reflecting resource utilisation, costs and patient satisfaction.

This flow chart is loosely based on a representation of flow of electronic messages in the health sector in the Report “IT brings Danish Health sector together” Pg.6, published on the public portal sundhed.dk.

Information from medcom.dk, IKAS and quality indicators of databases has been added to this to include every data point in the system, reflecting whether they are clinical, non clinical, and if the data reflects a economic value or not.

The stakeholders often use multiple platforms which cause some discrepancies in data formats and sharing and this number is indicated on the chart as well.

In 2014, EPIC, an American solutions provider has been chosen to overcome the many challenges posed by non synchronised platforms and data formats. In the years to come, EPIC is expected to create unanimity between the messaging systems and architecture, reducing lag and irrelevance.
The registration and any duplicate entries in the clinical databases depends on how each database is constructed. Since there are no overarching guidelines for building databases input fields, the area is characterised by different solutions. Also, irrespective of the database, typically the same variables especially from the LPR is what is double registered. These are about basic demographic information, administrative healthcare information and clinical information about diagnoses, procedures, examinations and medical history.

2.3.5 Double Registrations & Inconsistencies

Although the data is computerised, much of the data is manually entered and the nature of the administrative distribution causes the same data to be entered a multiple times. When this happens across different platforms used in the practice, it results in different formats of documentation, minor variations caused by human entry and thus it can be challenging to achieve a unified longitudinal data set without setting aside preparatory time for parsing the data.

Part of the problem of inconsistency stems from Denmark’s own digitalisation history. An early foray into digitising health records while providing long periods of data, often comes with data recorded across platforms that do not integrate very well or possibly support the same fields of data entry. Technically speaking, since Denmark was a frontrunner in digitalisation of its medical records, the data pool is inundated by a huge challenge of legacy systems and outdated platforms. Within the GPs alone, 16 different platforms are in use. The hospitals use 15 different platforms which are not the same as the ones used by GPs. Transfer of patient data is mainly textual (.xml) based between the systems except for when numerical data is used, for e.g. pathology reports.

Another instance is the restructuring of the municipalities in 2007 when 276 municipalities were reduced to just 98, resulting in codes that don’t match. Different collection periods, changed or altered variables all mean that there could be issues of inconsistent longitudinal datasets.

A double registration in this context can be defined as data with mandatory inputs into the LPR or other central registers but is also simultaneously collected in a clinical quality database.

Over the spring of 2010, the Sundhedsstyrelsen mapped and analysed double registrations across the system. 32 nationwide clinical databases, equivalent to 90 per cent of all registered patients in quality databases were mapped. The focus was the extent to which health staff use unnecessary time on record in quality databases,

*Documentation and exchange of data in the Danish Healthcare Data Landscape is clearly seen in the illustration hereunder.*

Illus 4. Det danske Sundhedsvæsenen

![Diagram of the Danish Healthcare Data Landscape](image-url)

because the database variables are also reported to a central repository. The variable was categorised as a double registration only if all outcomes for the given variable is registered in a central register. The survey shows that annually, almost 30 million double registrations were made between clinical databases and central health records. Between clinical databases and LPR / CPR alone, there were 25 million double registrations annually, equivalent to about 85 per cent. of the total number of double registrations. About 75% of annual double registration takes place in five of the clinical databases. Double registrations could be avoided by increasing integration with data from the central health records.

The Center for Register-based Research lists some interesting challenges in the existing Danish healthcare data.

Examples of inconsistencies include,

1) The Danish Civil Registration System (CPR) contains

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25 http://www.sum.dk/Aktuelt/Publikationer/Analyse-af-kvalitetsoplysninger-i-Danmark-juni-2010/Kapitel%204.aspx
The Data Documentation Initiative (DDI) is an international cooperation for setting metadata documentation standards for describing data from the social, behavioral, and economic sciences. Data is unanimously expressed in XML and the DDI has a specification on how metadata must be stored. It now supports the entire research data life cycle. DDI metadata accompanies and enables data conceptualization, collection, processing, distribution, discovery, analysis, repurposing, and archiving.

2.4.1 Platforms, Integration and connectivity- The Danish case

While the registers and databases have an impressive record of quality of treatments, outcomes of care and improvement initiatives and numerous guidelines at local, regional and national levels written over a long period of time, a rather obvious problem of integrating all these initiatives has surfaced. About 3500 practitioners across 2100 clinics in 98 municipalities use 16 different platforms to make a data entry of Primary health care. While mostly they accept and send the same data fields, there are differences which eventually affects the completeness of the data.

The case is similar with the hospitals. 60 public hospitals use 15 different platforms to record and exchange data. The chance to leapfrog into a futuristic data repository seems a bit challenging - both from a technological aspect and behavioural resistance from the large administrative work force.
2.5 Data for citizen access

Anyone with a CPR number can access their health data. The portal **sundhed.dk**, gives access to journals and entries made at every contact point with a healthcare professional. This gives the individual a good amount of personal data for basic understanding. To get overviews on societal health data and statistics, aggregated data is also made available for citizen use. To understand a particular health condition, citizens can access the portal **esundhed.dk**, which gives access to aggregated data from specific, nation wide registers with a possibility to select variables for viewing. **Danmarks Statistics** offers a rich repository of annually published, aggregated and analysed data. **Danskernesundhed** publishes its findings from nationwide surveys to offer a big picture view of the nation’s state of health and healthcare. The **Interaktiondatabase** describes drug interactions and citizens are given the possibility to check this online. **Sundhed.dk** also offers a huge repository of common illnesses and treatment, therapy and medication options for them.

2.5.1 Sundhed.dk

Sundhed.dk is an online portal that was established in 2003 to provide a common digital entry to reliable information about an individual's health and the Danish health system and at the same time create an opportunity to provide healthcare professionals with access to improved ways of communicating digitally between each other and with patients. The partners behind sundhed.dk are Danish Regions, the Ministry of Health and municipalities through Local Government Denmark (LGDK). As a citizen, one can log in with their CPR number and access their health records generated at the GP, reports from the hospitals and any associated pathological tests or any other contact points with other healthcare professionals. While most records are real time, pathological reports are still deferred by a few weeks.

2.5.2 e-Journal

The e-Journalen ("e-record") system gives patients and healthcare professionals digital access to information on diagnoses, treatments and notes from eHR systems in all public hospitals. 30–40 per cent of the hospitals also provide access to information on medicine and sample results from laboratories. By the end of 2011, the system contained health data on more than 85 per cent of the Danish population. Clinicians at hospitals have access to e-Journalen directly through the hospital's eHR system, while GPs can access the system through sundhed.dk. Furthermore, patients can also gain access to their own data via sundhed.dk.

2.6 Data for research access

All large institutions concerned in the collection of data provide an interface to apply for access to data. Researchers are requested to furnish details of their study for access. This procedure also applies to other socio-economic data sources which opens up possibilities for intersectoral research. Some databases are more parsed and better tagged than others depending on how the data was gathered.

As a case, consider the National Biobank that has a repository of over 16 million biological samples. The samples accessed by robots can be retrieved based on multiple variables - For example, it is possible to retrieve blood spots from diabetics of Danish origin, between a particular age and income window, having had a case of a broken arm, and with three children.

2.7 Data for commercial access

Commercial entities can apply for use of personal data across sectors. Their permission of use and application is governed by the Danish Research Ethical Council which is the approval body for all register based research.
3. Sources of information

Mainly, three types of data are used by public and private entities to steer or design healthcare products, services and for policy making:

1. Health survey data,
2. Information about general consumption patterns
3. Administrative data generated by the healthcare delivery system.

Data based on clinical care come from electronic health records, clinic-based administrative datasets, and government reimbursement datasets. Large-scale registries are generated and maintained by the Regions, state health authorities, professional societies, pharmaceutical and device companies, and the government. Clinical trials, whether publicly or privately funded, can function as rich sources of observational data, useful for exploring questions that go beyond their original hypothesis. Common features of all these types of data include an electronic format, predefined fields, and for most, large numbers that enable robust analysis.

Data collected through these various registers, clinical studies, pathology tests etc, can be broadly classified as clinical and nonclinical data.

Clinical data usually refers to a real time database that can be a data collective as any of the under:

Electronic health records - This is the most basic, yet vital data collected at the point of interaction between the healthcare provider and the citizen. It includes demographic information, diagnoses, treatments, prescriptions and medicines, pathology tests, hospitalisation, insurance, cost reimbursements etc.

Administrative data provides statistics and information on hospital inpatient and emergency department utilisation.

Health insurance data includes data on all touch points that provide a service reimbursable by the public health insurance and details of subsidies provided on certain treatment offers.

Disease registries contain data within a very specific range of fields relevant to the disease type. These would include registries for diabetes, cancer, heart disease, asthma etc.

Health surveys could be regional or national and contain data specifically collected for research purposes pertaining to behaviour, diets and lifestyle, quality and experience of healthcare etc.

Clinical trials data is registries of controlled and randomised studies conducted by hospitals, research centers and private companies.

Non clinical data includes psychological, behavioral and sociodemographic factors in addition to information about a patient’s relationships, neighborhoods and communities.

Healthcare data collected through the system reflect economic data - data that indicate infrastructural expenditures, medicine, treatment or therapy costs.

Information on the nationwide registers and clinical quality databases we found, are distributed across multiple sources, not one giving a detailed overview of the landscape. While the National Board of Health (Sundhedsstyrelsen) lists a majority of the national databases, details of administrators, quality indicators and data variables, period of data collection and access is distributed across many websites. Hereunder is a list of sources of information we have used to compile the list of national health registers and clinical databases. Refer to Table 2 for list of websites with information on ehealth records

3.1 National registries

From 1 March 2012, all data on the state of public health and data concerning health service activity, economics and quality has been consolidated at, and analysed by, Statens Serum Institut (SSI). The data is utilised for national and local authority tasks and made available for research and analysis purposes in the field of health.

The registries comprise data on the nation’s health, morbidity and mortality, together with data on healthcare sector organisation and economics. The national registries publish statistics on a regular basis, and offer access to data extraction. In addition, extracts from the registries are provided for activities such as analysis, research and planning.

Examples of National registries include, the Register for causes of death which has information on death and relating causes based on death certificates issued from 1875, or the National Patient Register.
Table 2: Health agencies with information on clinical databases.

<table>
<thead>
<tr>
<th>INSTITUTION</th>
<th>INFORMATION ON DATABASE</th>
</tr>
</thead>
</table>
| The National Board of Health  
Sundhedstyrelsen  
www.sst.dk                                                      | The website offers a detailed guide of all the applications needed to conduct and approve clinical trials. |
| Statens Serum Institute  
www.ssi.dk                                                                  | A detailed list of national health registries classified broadly is presented with registration and reporting practices in the case of important national registers and access information to most. Clinical quality database are not listed but SSE establishes requirements for the approval of the clinical databases. Registration in the clinical databases, approved by the State Serum Institute, can be done without the consent of the individual patient. |
| e-Sundhed  
eSundhed.dk                                                        | Under health records, eSundhed offers aggregated overviews of specific national registers over the entire period of data collection. Specific variables can be chosen for comparative display. |
| National Biobank  
www.biobankdenmark.dk                                                      | Explains the biobanks in Denmark and how data from various registers can be combined. Gives researchers online access to combined data from all the biobanks participating in the Danish National Biobank initiative. |
| Datatilsynet                                                              | All legal requirements required to start, maintain and access registers and databases pertaining to personal data and how they may be processed. |
| Kompetencecenter for Klinisk Kvalitet og Biostatistik, Nord  
www.kea.au.dk                                                            | List of nationwide clinical databases with purpose, indicators, description, data, organisation of steering committee, contacts within scientific institution, competence center and region. |
| Kompetencecenter for Klinisk Kvalitet & Sundhedsinformatik  
Competence Center for National Clinical Databases, East  
Region H  
Region Hovedstaden  
www.regionh.dk                                                               | List of nationwide clinical databases with format of the database explained along with purpose, indicators, data collection, annual reports, organisational contacts, current status and funding. Some regional databases within the Capital Region are also listed. |
| Competence Center for National Clinical Databases, South  
Center for Clinical Epidemiology  
Odense University Hospital  
www.ouh.dk                                                                  | Very brief information on only national databases that are populated and maintained by the center with details of those in charge and relevant web links. |
| Center for Register-based Research  
Center for Register Forskning  
rkkp.au.dk                                                                   | A rich repository of all nationwide registers (non-health included). Very brief information on each, but contains contact details and organisational structure of the database. |
| Regionernes Kliniske  
Kvalitetsudviklingsprogram (RKKP)  
www.rkpp.dk                                                                  | Links to clinical databases, annual reports, their own websites (in case of important ones like diabetes or cancer). |
| Center for Integrated Register-based Research  
National Institute for Public Health(NIPH)  
Statens Institut for Folke Sundhed (SIF)  
The European Centre for Register Research (ECERF)  
http://www.si-folkesundhed.dk/                                             | Excellent overview on application & approval procedures for inter-register research, especially useful for interdisciplinary predictive analysis. |
(NPR) which collects information on diagnoses and operations performed in hospitals since 1977, or the National Health Service Register (NHSR) which since 1990, collects information from primary health care contractors about quality of treatment and services, or the Pathology Register which from 1997 holds data on all pathological studies conducted by the country’s pathology departments etc.

3.1.1 Clinical databases

A clinical quality database is a registry containing selected measurable indicators which, based on individual disease courses, serves to shed light on either parts of or the overall performance standards within the health service and outcomes for a limited category of patients. These databases are all restricted to a diagnostic group, a medical speciality or procedure. This means that separate databases are maintained for patients with conditions such as COPD, breast cancer, cardiac insufficiency etc.

*Illustration 5: Clinical Databases - Construct & Workflow*

This depicts the administrative construct of clinical databases in Denmark. Each stakeholder contributes to the data quality both by intrinsic domain knowledge, and computation infrastructure. The representation of Danish Regions in the maintenance of a database ensures nationwide outreach for data collection. The establishment of the database itself is overseen by Datatilsynet where anyone wishing to setup a database applies for permissions and further clearance from the Danish Research Ethical Council. Formats for setting up the database are established by the Datatilsynet.
The data are used for monitoring the quality of treatment in order to assess any underperformance and potentials for improving quality of care. There are currently approximately 60 national clinical quality databases, which in combination cover approximately 60 categories of medical conditions.

Examples of clinical quality databases could be the Colorectal Cancer Database which contains diagnostic, treatment and follow up on all colorectal cancer patients from 2001, or the Hysterectomy Database that since 2004 contains diagnostic, treatment and follow up information on all women who undergo hysterectomy, the Cytogenetic Register which since 1968 contains information on persons who have undergone prenatal chromosomal diagnostic procedures.

The clinical databases are organised under a public authority (for e.g, the Regions) for reasons of administrative ownership and data security and based within a scientific institution to ensure professional support, consensus on indicators and peer acceptance. The databases are attached to one of three Centers for Competence for epidemiology and Biostatistics who provide IT and workflow advice and bring expertise on data analysis.

3.1.2 Cohort Studies

Over the last 50 years numerous cohort studies have been conducted providing ample opportunity for researchers to revisit contextual data with new research probes.

Cohort studies are often established with a specific focus (for e.g. to study the establishment, development or progress of a particular condition). Yet in a context like Denmark, where personal data has been meticulously documented and digitised for decades, cohorts assume a new dimension. The same data can be reassembled and also combined with other socio-economic data pertaining to the same person to derive new findings.

An example of a broad spectrum cohort is the Danish National Birth Cohort where children are followed continuously through their childhood (pre-teenage year) via qualitative questionnaires and quantitative recordings of vital statistics at regular intervals.

This data can be understood with data on their sensorial and lanuguage development at kindergartens, education records at primary school, data on other members of the family, parents income, residence etc. which have broader implications if considered for future socio-welfare frameworks and governmental policies.

Another such study is the Diet, Cancer and Health cohort which in its very nature is broad, recording lifestyle and its effect on overall onset, treatment and therapy of cancer. Such studies could generate data points that are relevant to other sectors such as the agriculture and food industry, manufacturing industry at large or feed into fundamental genome research.

The data will further reflect on the economy of persons and their families and thus data is very valuable in the welfare model as every instance of welfare payout (unemployment, rehabilitation, support etc.) is only adding burden to the system.

While these are very large scale cohorts, smaller cohorts can be very valuable too. The Gerda Frentz Cohort for example is not just another cancer register. The true incidence of non melanoma cancers is a very vital information in the nordic populations due to their predisposition to skin cancers co-affected by their environment (sun and UV radiation), diet and subsequent absorption of food and importantly lifestyle factors like sun based activities which prolongs exposure and risk.
Here are some of the largest cohorts conducted in Denmark:

**The Danish National Cohort Study (DANCOS)** is a nationally representative public health survey based on linkage of information in the repeated Danish Health Interview surveys, 1986–2005.

**Diet, Cancer and Health** is a Danish prospective cohort study aimed at investigating the associations between dietary habits, lifestyle, and cancer development. The participants were recruited during 1993—1997.

**The Danish National Birth Cohort (DNBC)** aims to study the period from conception to early childhood and examine how this period influences health conditions at later stages in life. Determinants for reproductive failures, identifying pre- and perinatal determinants for important health problems in childhood and improving the infrastructure for future studies of health and disease using a life-course perspective are key. 101,042 pregnant women were recruited in the first trimester at the first antenatal visit at the GP’s during a massive enrolment plan between 1996-2002 and 96,986 children resulting from the pregnancies are being followed through.

**The Danish HIV Cohort Study(DHCS)** collects data to study temporal changes in the demographic composition of the HIV population. The effects of the antiretroviral therapy is recorded alongside mortality, any new AIDS-defining events etc. All clinics treating HIV infected patients in Denmark participate in DHCS. As treatment is restricted to eight departments of infectious diseases and medicines are delivered free of charge, medicines cannot be purchased from pharmacies in Denmark.

**The Soon-Pregnant Cohort Study** is a web based study investigating risk factors for delayed fecundability and miscarriage. Women are between 18-40 years old, trying to become pregnant and not using contraceptives or fertility treatments. Feasibility of web based cohorts is also being explored in this study.

**The Danish Newborn Screening Biobank (NBS-Biobank)** collects blood spots of all newborns to screen for Phenylketonuria, congenital hypothyroidism and toxoplasmosis in order to improve screening, statistics and eventually diagnostics later in infancy.

**The Gerda Frentz Cohort (GFC)** studies the profile and true incidence of non-melanoma skin cancer and was initiated as the registration of cancers was incomplete in the Danish Cancer Registry.

**The DANVIR Cohort** records prevalence and mortality with chronic viral hepatitis (Hep B, Hep C) and its comorbidities with cancer and cirrhosis.

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20 Data collection began in 1996, and was nationwide by 1999. Danish Epidemiology Science Centre, Statens Serum Institut.
21 http://www.cls.ioe.ac.uk/page.27.aspx?&sitesectionid=342&sitesectiontitle=Danish+National+Birth+Cohort
22 Data collected from 1995 onwards. Department of Infectious Diseases, Copenhagen University Hospital.
24 Data with dried blood spots collected from 1982 onwards. Department of Clinical Biochemistry, Statens Serum Institute
25 Data collected from 1995. Department of Clinical Epidemiology, Århus University Hospital.
26 Data has been collected once from January 1 1995 to end 2006. Updates are planned at intervals of three years.
3.1.3 Genome Data in Denmark

It appears that genetic research in Denmark is not specifically funded by private firms, scientific educational institutes or government institutions alone. Rather, funding and support seem to be co-established and funding is mostly to large research initiatives, genomic efforts being a prominent path.

Genome research has benefitted with numerous public private partnerships and efforts initiated by Danish private companies like Novo Nordisk A/S, Carlsberg Laboratory, Statens Serum Institute, Christian Hansen's Lab, Danisco, Leo Pharma, Lundbeck Pharma, Neurosearch, Nordic BioScience Diagnostics A/S etc.

The Danish Parliament in 1991, recognising the need for channelising research, funding and intellect in fundamental research setup The National Research Foundation40 (Danmarks Grundforsikningsfond) as an independent organisation. Funding is effected through Centers of Excellence (CoE), but various programs and initiatives towards the internationalisation of Danish research is supported.

See Appendix for List of CoE for healthcare in Denmark

Genome Denmark41 is a national platform for sequencing and bioinformatics involving universities, hospitals and private companies and one of their strongest research agendas is to use genomic research for improved efficiency of personalised treatment and healthcare delivery in the future.

The Danish Reference Genome Project44 is a database of 30 (of an expected 150) individual, fully mapped genomes from the Danish population. It allows detailed analysis of the individual genetic differences between the individuals and is seen as a starting point for individualised treatments in the future. The database is small, thus providing a benchmark on who is a normal Dane and a perceived deviation from this normal, thus a cause of illness. The database is administered by Genome Denmark.

The Danish Platform for Large-scale Sequencing and Bioinformatics is a collaboration between the University of Copenhagen, the Technical University of Denmark (DTU), Aarhus University and Aalborg University and will co-operate with Bavarian Nordic A/S, Beijing Genomics Institute Europe A/S and Genomic Expression ApS. This platform brings Beijing Genome Institute (BGI) Europe to establish what will be the world's largest and most elite genome research lab in the world.

3.1.4 Biobanks

Danmarks Nationale Biobank

The Danish health system has routinely collected biological material from a large number of individuals and this is documented and physically stored at the National Biobank.45 The main purpose of the Danish National Biobank is to give scientists from Denmark and abroad overview and access to more than 16 million biological samples in both existing and future collections.

The Danish Biobank Register gives researchers online access to combined data from all the biobanks participating in the Danish National Biobank initiative. Through national collaboration large biobanks, based at hospitals, universities and other research institutions in Denmark, regularly submit data to the Danish Biobank Register. Data from the biobanks are linked to disease codes and demographic information from national

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40 www.dg.dk
41 www.genomedenmark.dk
42 http://www.genomicepidemiology.org/index.html
43 www.cbs.dtu.dk
44 http://www.genomedenmark.dk/english/about/referencegenome/
45 www.biobankdenmark.dk
Anonymous data sets are made available to researchers around the world through a web-based search system. So far, information from the following biobanks are available through the Danish Biobank Registry:

1. The Danish Patobank (approx. 12 million tissue samples from national hospitals)
2. The Danish Cancer Society’s project biobank “Kost, kræft og helbred” (samples from 57,000 cohort participants)
3. The new DNB biobank at Rigshospitalet (50,000 samples collected annually)
4. The Cancer biobanks (de Kliniske Kræftbiobanker) Samples from the Danish National Birth Cohort (300,000 samples)
5. Blood spots from all newborn Danes since 1976 (1.9 million samples)

3.1.5 A note on social and economic data

Economic and social data is collected with as much breadth and depth as healthcare data in Denmark, making data analysis rich and addressing multi party needs.

The Danish Data Protection Agency and the Danish Data Archive are still responsible for the overall authorisation and archival of this data but the collection is distributed at the municipality, regional and national levels. Aggregated analysis of this data can be found with Denmark’s Statistics and to some extent on Danskernessundhed.dk and eSundhed.dk

4. Accessing the health data

While healthcare data in Denmark looks apparently well documented and retrieval of huge volumes of data pose no doubt, there are still technical and administrative frameworks that regulate the access of data and its resolution. Procedurally, some registers can be accessed at the research institution administering the data with due permissions while some data is on an individual level needs approval of multiple agencies for access and analysis. A typical approval process might involve the Datatilsynet (Danish Data Protection Agency), Statens Serum Institute and Statistics Denmark. Agencies like CIRRAU facilitate in organising research within the premise of necessary paperwork. This could take anywhere between 12-18 months.

For further reading refer Sec. 4.6

4.1 Legislation

Data entry, access and retrieval in Denmark is governed by the Act on Processing of Personal Data (Persondataloven)\(^\text{46}\) The Act on Processing of Personal Data (Act No. 429 of 31 May 2000) entered into force on 1 July 2000. The regulations of the Act on Processing of Personal Data apply to the processing of personal data if the processing is conducted for scientific or statistical purposes.

Personal data is understood as data about a person that directly or indirectly can be identified.

Processing is understood as all forms of handling of data, i.e. collection, registration, storage, application, etc.\(^\text{47}\)

However, the act does not apply to data already made anonymous. Anonymous data is defined as any data that cannot be traced back to an individual.

4.2 The Danish Data Protection Agency

Datatilsynet

The Data Protection Agency\(^\text{48}\) is the state authority that oversees the Act on Processing of Personal Data. The agency consists of a Data Council (DataRåd) - and a secretariat. The agency maintains an inventory of all databases maintained in the country under the category “Fortegnelsen”. However this is not offered for public use as a handbook or directory of databases yet.
4.3 The Danish Data Archive

Dansk Data Arkiv

The Danish Data Archive (DDA) is Denmark's national social science data archive acquiring, preserving and disseminating data generated from social science, health science and history. Through an agreement with the Danish Data Protection Agency the DDA preserves data materials containing personal identifiers. The data and personal identifiers are stored separately and a special permit is required for the access to the data. The DDA adheres to metadata documentation guidelines set by the DDI.49

4.4 Danish Research Ethical Council

Den Nationale Videnskabsetiske Komité

Under the Committee Act, it is the responsibility of the committee system on health research ethics to ensure that from a research ethic point of view, health research projects are carried out in a responsible manner, and that the rights, safety and wellbeing of trial subjects participating in such biomedical research projects are protected, while at the same time possibilities are being created for the development of new, valuable knowledge.50 They are the single authorising body for all register based research for both research and commercial purposes.

4.5 The Danish Council of Ethics

Etiskråd

The Council was established in 1987 as a result of a directive from the Parliament to advise the Parliament and other Government agencies on new bio and gene technologies, while creating discussions and debates around this area. Members of the council are honorary and elected for their experience in this field. The Council advises and creates debate on biotechnology, which affect human life, our nature, the environment, and food. The Council also works with ethical issues related to the healthcare sector.51

4.6 Challenges of intersectoral data access

Data transfer between sectors in many cases needs approval from the patients. This means that while data coverage is complete at the organisational level, extracted databases may not reflect the true incidence of cases. For example, an incidence of hospitalisation will be reported to the GP only on approval from the patient. Or a case of psychiatric treatment at a hospital can be kept out of the patient’s journal if the patient so wishes, and only reflected in the hospital's own case file. This choice of disclosure is a vital part of the trust framework that data collection in Denmark builds on.

The role of the Act on Processing of Personal Data and the Danish Research Ethical Council are nuanced in that the transfer of personal data between registers (for example, between the hospital's register and a Cancer Register, or the case of information on hospitalisation being intimated to the GP) is governed by the Act itself while the extrapolation of data from any of the registers is under the purview of the Danish Research Ethical Council and prior approval is mandatory.

However, some agencies are helping bridge this gap by facilitating help with paper work and legislative issues. For example, the following agencies are useful references:

- **Center for Register based Research (NCCR)** is a national institution, established in 2000, and embedded in the Faculty of Social Sciences in Aarhus in 2005, contributes to the integration of health sciences and and social register based research to strengthen the social scientific use of register data. The center, apart from advice, helps in the practical participation in researches of this kind.52

- **Center for Integrated Register-based research (CIRRAU)** located at Århus University facilitates interdisciplinary research in the academic areas of Social Sciences, health sciences and elements from Natural Sciences based on databases and biobanks within a framework of translational population studies. Five categories of data constitute the CIRRAU data resource:
  1. The Family Relations Database
  2. Economic, Social and Contextual Data
  3. Prescription Data
  4. Geocodes
  5. Data Contributions from Participants

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49 http://samfund.dda.dk/dda/default-en.asp
50 http://www.cv.ksum.dk/
51 http://www.etiskraad.dk/
52 http://ncc.au.dk/am-centret/
53 http://cirrau.au.dk/
5. Society as a Cohort

The data from various national registries and condition-specific clinical databases are linkable with varying degrees of effort and parsing to an individual's level. The challenge if any, is of data completeness. The Danish National Health Service Register for Primary Care (Sygesikringsregisteret, NHSR)\(^4\) contains information about the activities of health professionals contracted with the tax-funded public healthcare system. These are general practitioners (GPs), practicing medical specialists, physiotherapists, dentists, psychologists, chiropractors, and chiropodists. The purpose of the register, which is within the remit of the National Board of Health (Sundhedsstyrelsen), is to document activities in primary health care for administrative use and to contribute to research in public health. Since this register is concerned with reimbursements, it is considered fairly complete. In this context, every person with a CPR number, i.e anyone legally residing in Denmark leaves a trackable and comprehensible trail of data on quality of life and consumption of resources.

Presented here are three different scenarios of viewing a person’s health data along his lifetime, which represented aptly, presents itself as a cohort and represented collectively, is a cohort conducted on an entire society.

Illustration 6: Society as a Cohort - A scenario view on how data is populated and could be accessed over a lifetime.

A sample of a healthy person’s health data gathered through a lifetime. Numerous screening efforts for a spectrum of conditions results in population data that is rich with health indicators that help determine population health trends, genetic predispositions and lifestyle correlated to life stages. This scenario view gives us an idea of how meticulously our lives are documented, even in the case of a largely healthy life with few interactions with the healthcare system.
Furthermore, the Danish population is considered as being largely homogenous and non-transient which is ideal for long term population (also gene-pool) studies.

With a wide range of register based studies, cohorts can be easily assembled to observe developments across a group for specific factors. An example is the Borberg cohort of patients with neurofibromatosis that was established in 1940 and was reinvestigated in a follow-up study 46 years later. Sørensen et al revisited this established cohort and linked to data from the DCR to follow patients for the development of malignant neoplasms after diagnosis of neurofibromatosis. The registry-based approach was also used in the same study to investigate risk factors and survival.

Illustration 7: Society as a Cohort - Scenario of accident and physical & mental rehabilitation cases

From such a scenario view, it is easier to understand and infer the treatment quality in hospitals and post trauma care. It is very relevant to varied sectors from transportation and traffic (for e.g. response time), disbursement of welfare funds (for e.g. unemployment in case of long rehab or disability) etc. If the data can be parsed and visualised in interesting ways. The various registers that would / could be populated by a single incident are shown here under. When seen in conjunction from birth and various other registries that are populated as part of the healthcare, it is interesting to analyse the incidence of accidents, quality of treatment and thus healthcare.

An accident which involves admittance in a hospital is treated as a case of secondary care. All documentation pertaining to this episode is maintained only at the hospital, including medications given and any tests conducted. Should the patient have any degree of rehabilitation provided, this is also kept within the hospital records. All this data is shared with the GP only after prior consent from the patient or discharge. If the patient so wishes, the entire data or a part of it can be kept unreported, exclusively within hospital records. This is very interesting when considering the true breadth of all the registries.
Illustration 8: Society as a Cohort - Scenario of screening, treatment and care in chronic ailments

In this wellness journey of a person, some instances of chronic care have been mapped. Specific registers have been instituted for these illnesses. Viewing the registers as different scenarios allows one to see the relevance of the registers. This scenario marks the registers that reflect the life-long use of resources in a chronic condition, treatment, efficacy and outcomes. Much can be learnt about demographic tendencies in developing chronic illnesses and the state’s role in prevention and cure. Some reflecting databases are also mentioned here, as the earliest screening factors or diagnosis has happened through other procedures. Read in tandem, registers across these stages could provide vital insights into early screening, genetic predisposition and lifestyle.
5.1 Demographic focus: Women, Children, Elderly & Veterans

Several registers have been established to study specific demographic groups, as clinical databases, registers and cohort studies. The health of women has been a particular area of focus with cervical cancer, mammography screening, breast cancer, gynaecological cancers being important. Reproductive health of women is especially important with other population indicators and thus quality of birthing, IVF, abortion, pregnancy screening, early pregnancy related abortions, birth & complications are all registered. Cohorts have been established to study pre-pregnancy, pregnancy and eventually birth and development of a child in close relationship to its mother thus giving researchers a chance to develop population prognosis especially with health indicators for genetically and nurture induced predisposed conditions.

Children, with some registers concerning birthing share register data with women, but on their own have several health registers especially for conditions like childhood diabetes & cancer. Together with health records maintained at schools, this can be extrapolated with family data and education data to analyses data for welfare schemes, future job markets, diet & nutrition studies, mental health etc.

Geriatric care is a huge component of social welfare & healthcare, which gives no surprise to detailed information maintained Nationwide database of Geriatrics, the Danish Palliative Care database and the Danish Dementia Database. Apart from these there are other socio-economic databases maintained by the different kommunes on spending for the elderly in home care, institutional nursing, food delivery, transport etc.

The Armed forces maintain the Sessions Register, but we have been unable to find further information on this and related registers in the scope of this study.
Illustration 9: Women and Children: Unique and symbiotic datasets for future population studies

A specific case of registers pertaining to women and children is considered here. While most of these registers concern demographic specific data, some are about reproductive health, birth and early infancy. These registers are closely linked by their very nature and have been shown as such in the illustration.

The larger Danish cohort studies on Soon to be pregnant women, and child development could be read with smaller nation wide registers on pregnancy screening, complications, birthing and post natal care. They are insightful on various levels - from lifestyle to life stage - a clear insight can be reached upon co-related demographic shifts, patterns in income groups and this could have huge inputs in pharmaceutical research and go-to market strategy for such companies.

The State benefits from this understanding for a better structuring of its welfare funds and infrastructure.

While some of these registers are populated based on true incidents, many are populated by surveys and more recently entire cohorts are being tested with an exclusive online platform with only online engagement with participants. The Soon to be Pregnant study is one such cohort being conducted only through online participation.
6. Mapping the Databases

With a plethora of registers, databases, clinical studies and cohorts, it was imperative to see them mapped on the body - the body being the metaphor for areas of study. The obvious inferences were the areas where a lot of research is done, but it also revealed the many areas of concern where there is a lack of systematic data collection.

The many registers that have been enlisted in the report are essentially specific health condition data drawn from the National Patient Register (NPR) and categorised into a specific register. So the individual registers do not provide any extra breadth of information than the NPR. Yet, the depth of clinical data specifically logged into specific registers makes cross sectoral research rich and diverse. Individual factors can be measured against other socio-economic factors to project new connections and value for other stakeholders.

The body view of the registers also allows one to see the different research strategies adopted to study a particular area - For example, female reproductive sciences in the Danish population is now studied with smaller registers collecting nation wide data on gynaecological cancer, cervical cancer, birthing and abortion. There are specific registers recording IVF treatment and abortion in early pregnancy. Further there are cohort studies that are recording the months leading up to conceiving (pre-pregnancy environment and factors) and birth and child rearing. This way, a part of the selected population has a deeply documented wellness journey which could be very valuable for other stakeholders.

Pharmaceutical research stakeholders who also invest heavily into health research delve into huge volumes of anonymised data for research on new drug delivery or their future strategies.
Studies and registers pertaining to men and women are presented in this illustration. The numbers correspond to the List of Registers presented in the Appendix to this report. This allows us to see the health areas where we have the largest amounts of data which is reflective of population health and governmental priority.

Please refer to the appendix for The List of Registers.
CONTEXTUAL EXTRAPOLATION OF HEALTHCARE DATA

Data for Calculation and verification of business cases.
Demographics, Segments and Costs

The Danish health care data landscape is fragmented but very rich. When this dataset is combined with demographic from Denmark Statistics and budget allocations from various regions, it will provide an in-depth view into the segment of healthcare and how the spending patterns are organised. This is a vital piece of market analytics that help existing companies but also point to new areas that startup and foreign investors could take deep interest. We foresee new service possibilities, optimisations and novel products to fill the any gaps that are emerging from the landscape.
Data to quantify non-economic effects of new solutions.
Support Innovation Decisions

Interestingly the data available in the Danish healthcare system is a mix of qualitative and quantitative data. A large pool of journal entries and text logs could actually be mined to extract a semantic model that can inform and support decision making on levels like quality of service, quality of counselling and support etc. There are numerous extrapolations that might support non economic indicators that would make the overall system better for the end user or patient support.
Data for basis of new solutions, collaborations

Data is the new currency of the digital age. The Danish health data is not just a goldmine waiting to be tapped but also could form the basis for totally new types of solutions – esp new collaborative ones. Traditionally the diagnosis to care to prognosis pathway has been a fragmented journey both in terms of data and patient care. Modern data technologies will create a more unified opportunities for stakeholders to engage in a more seamless data landscape. This cementing of data process will also enable new business cases to emerge from this confluence. This collaborative culture around health care innovation fuelled by data would be a strong growth market and enormous potential – esp for non traditional players.
Data for pattern analysis at large scale for planning and research.

The Danish healthcare system is quite intensive (excellent raw material) but is yet to see the emergence of large scale pattern recognition models. The cause – effect relationship and spotting of trends have happened in relative isolation based on disease areas (e.g diabetes) or demographic basis (e.g elderly). This is mostly due to the professional specialisation and administrative legacy of many of these initiatives. This is going to change rapidly with the introduction of many big data technologies which will enable the cross finding and correlation mapping of various data sets at very large scale. There are numerous opportunities to be exploited in terms of large scale epidemiological studies, market analysis and better optimisation strategies based on macro-economic view of the health care system. This though would need extensive cross organisational collaboration and reduction of administrative silos. There are indications of such an approach already being used in research – esp genetic and phenotype. This approach is yet to be systematically done on administrative and economic aspect of the healthcare system.
The Danish health care data is perhaps the earliest of its kind and thus, is a fantastic opportunity as well as a challenge at the same time.

The richness and depth of data combined with a unique person identification number is a gold mine of data driven opportunities for new types of services and products to evolve. On the other hand the legacy of the old systems means, many of these datasets are fragmented and reside in numerous organisational and technological silos.

In this study, we realised the extent to which new possibilities could emerge in tandem with new technological trends. Some of the new technological trends that will highly influence the data landscape of the Danish healthcare systems are:

1. Big data analytics - the rise of cloud enabled solutions for identifying and analysing new treatments.
2. Quantified self - Patients being empowered with data collation tools and devices at home.
4. IOT in hospitals - sensor enabled data collection of both therapy as well as patient status.
5. Software as a service - new forms of services that are entirely enabled by software tools
6. Service robotics - the automatisation and augmentation of many basic services esp. in convalescence and elderly care.
7. Personalised Medicine - tailor made therapy based on genetic as well as physiological data.
8. Telemedicine - remote care enabled by new communication technologies
9. Tertiary care - the emergence of new types of services that are more focused on overall wellbeing rather than diseases.
These trends are global and some of them will be pioneered in Denmark and many in other parts of the world but the foundation for the fostering of these new innovations are deeply engrained in the Danish Society. This is due to 5 major factors that are unique to the Danish system:

1. Very rich data sets from many decades - the basis of many types of new data enabled services

2. Good governance and regulation on data privacy - balanced by an open data approach to non-sensitive data

3. Data Policy and politics - a well debated but progressive policy environment that works in the favour of citizens and end users.

4. Pharma and health tech cluster in greater Copenhagen area and neighbouring southern Sweden.

5. Pervasive internet and data connectivity across the entire country.

We can foresee the rise of a new type of health care economy that is driven by entrepreneurship, public-private partnerships and university-based research. These are clear trends and the signals to support them are visible though there is a long way for these to flourish into a rich ecosystem with the right business models. The coming decade will be the rise of the data-driven economy for the Danish health tech cluster.
The Danish Healthcare system is abundant with opportunities. Denmark has had a long tradition in providing advanced healthcare with universal access to all its citizens. The quality of healthcare depended for long on good clinical practice supported by purchasing modern technology to support it. At this point in time, the confluence of good medicine and management alone is not enough. The new paradigm of healthcare is clearly moving towards a system that is based on collaboration, data driven and precision-tailor made medicine. This combined with change in social structures influenced by media and internet technologies, shift in demographic etc will make it necessary for the Danish healthcare system to evolve itself and the logical next steps as a recommendation could be as below:

1. **The use of data driven methods to drive public procurement** -
The public sector is the largest buyer of healthcare in Denmark, its a clear value addition to have a more accurate, evidence based tendering process. There are huge efficiency gains to be made and the public-private partnership initiatives already point to the right directions. Still the purchasing of healthcare services and products will have to be smarter for both cost-benefit of the system itself but also to nurture pioneering systems and innovation. Luckily the Øresund region has a huge health-tech industry that should be an excellent collaborator in the process.

2. **Using connected technology with a more collaborative clinical practice** -
The interaction between the patient and caregiver will undergo major shifts driven by the quantified self, web technologies and communication technologies. This will question the current way in which both primary and secondary healthcare sector is organised. Its a natural progression to build new systems to support this paradigm in the participatory traditions of the welfare model.

3. **A data driven approach to preventive healthcare** -
Following advances in genomics, bio-informatics, predictive analytics, sensor driven data gathering etc is a clear global tendency that will change citizen expectation very fast in Denmark, considering how fast and early on the social media trend is adopted in Denmark. Having the policies and governance in place to embrace this trend would be crucial link to growth for this sector.

4. **The myth of the rich data set in Denmark** -
Paradoxically the Danish healthcare system is a gold mine of data to drive the above three paradigms due the excellent data quality and density available. Though the data is trapped in organisational silos and data architecture is not designed for collaborative use at scale. There is an urgent need to build unified data interchange protocols and allow faster turnaround for data mashups to happen.

These above paradigm shifts are also ripe with opportunity for delivering better healthcare to
citizens but also nurturing entrepreneurship and growth for companies. The following are some clear pointers that could pave the road to support healthy growth.

1. *Digital Marketplace*

Copenhagen Healthtech Cluster could enable a digital market place that brings together research, clinical practice and commercial partners in tandem with public agencies and hospitals. This marketplace would need to be very governed and regulated for it to be a trustworthy exchange of value. It has to be imagined as an online platform where insights and ideas blend in a very practical context.

2. *Sandbox development environment*

To support the Digital Marketplace it’s highly recommended to create a virtual sandbox that has a wide selection of anonymised sample data from the various databases identified in this report. This will have to be wrapped in a modern API (Application programming interface) and due care should be given to data availability, quality and privacy. The participants in the sandbox should be able to logically scale the solution they prototype by allowing a pre-screened and easy connectivity at the right terms. This would be vital to make this a long lasting system. This sort of facility would make it much easier for companies and startups to prototype solutions faster in collaboration with clinical and regulatory settings.

3. *Smart Procurement*

The biggest and most obvious beneficiary of a digital marketplace would public purchasers who can both seed specific problems and needs into the system. If there is a critical mass of participants it would create healthy competition letting the most innovative as well as cost effective solutions to foster.
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<td>Clinical quality</td>
<td>Region H</td>
<td>Peter de Nully Brown, <a href="mailto:peter.brown@regionh.dk">peter.brown@regionh.dk</a></td>
<td>Tel: +45 3545-1128</td>
<td>Sofia Kyndesen</td>
<td><a href="mailto:sofia.mi.jin.spaabaek.moe@gmail.com">sofia.mi.jin.spaabaek.moe@gmail.com</a></td>
<td>Region H - Kompetencecenter Syd</td>
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<tr>
<td>43</td>
<td>Blood, Condition</td>
<td>Landsdækkende kliniske databaser</td>
<td>Den Haematologiske Fællesdatabase - Myelomatoses</td>
<td>2005-2006</td>
<td>Clinical quality</td>
<td>Region H</td>
<td>Peter de Nully Brown, <a href="mailto:peter.brown@regionh.dk">peter.brown@regionh.dk</a></td>
<td>Tel: +45 3545-1128</td>
<td>Sofia Kyndesen</td>
<td><a href="mailto:sofia.mi.jin.spaabaek.moe@gmail.com">sofia.mi.jin.spaabaek.moe@gmail.com</a></td>
<td>Region H - Kompetencecenter Syd</td>
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<td>44</td>
<td>Orthopaedic</td>
<td>Landsdækkende kliniske databaser</td>
<td>Dansk korsbåndsregister</td>
<td>2005-2006</td>
<td>Clinical quality</td>
<td>Region H</td>
<td>Anna Hjelm, KCKS-West, E-mail: <a href="mailto:Anne.Hjelm@stab.rm.dk">Anne.Hjelm@stab.rm.dk</a>, tel 7841 3987</td>
<td><a href="http://www.laeger.dk/portal/pls/portal/!PORTAL.wwpob_page.show?_docname=10765412.PDF">http://www.laeger.dk/portal/pls/portal/!PORTAL.wwpob_page.show?_docname=10765412.PDF</a></td>
<td>Peter K. Estrup, Tel: 7841 3987</td>
<td><a href="mailto:mette.kramer@livstilregionh.dk">mette.kramer@livstilregionh.dk</a></td>
<td>KCKS, Vest: Mette Kramer Pedersen</td>
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<td>Landsdækkende kliniske databaser</td>
<td>Dansk knæalloplastikregister</td>
<td>2005-2006</td>
<td>Clinical quality</td>
<td>Region H</td>
<td>Anna Hjelm, KCKS-West, E-mail: <a href="mailto:Anne.Hjelm@stab.rm.dk">Anne.Hjelm@stab.rm.dk</a>, tel 7841 3987</td>
<td><a href="http://www.laeger.dk/portal/pls/portal/!PORTAL.wwpob_page.show?_docname=10765412.PDF">http://www.laeger.dk/portal/pls/portal/!PORTAL.wwpob_page.show?_docname=10765412.PDF</a></td>
<td>Peter K. Estrup, Tel: 7841 3987</td>
<td><a href="mailto:mette.kramer@livstilregionh.dk">mette.kramer@livstilregionh.dk</a></td>
<td>KCKS, Vest: Mette Kramer Pedersen</td>
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<td>Clinical quality</td>
<td>Region H</td>
<td>Anna Hjelm, KCKS-West, E-mail: <a href="mailto:Anne.Hjelm@stab.rm.dk">Anne.Hjelm@stab.rm.dk</a>, tel 7841 3987</td>
<td><a href="http://www.laeger.dk/portal/pls/portal/!PORTAL.wwpob_page.show?_docname=10765412.PDF">http://www.laeger.dk/portal/pls/portal/!PORTAL.wwpob_page.show?_docname=10765412.PDF</a></td>
<td>Peter K. Estrup, Tel: 7841 3987</td>
<td><a href="mailto:mette.kramer@livstilregionh.dk">mette.kramer@livstilregionh.dk</a></td>
<td>KCKS, Vest: Mette Kramer Pedersen</td>
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<td>Region H</td>
<td>Anna Hjelm, KCKS-West, E-mail: <a href="mailto:Anne.Hjelm@stab.rm.dk">Anne.Hjelm@stab.rm.dk</a>, tel 7841 3987</td>
<td><a href="http://www.laeger.dk/portal/pls/portal/!PORTAL.wwpob_page.show?_docname=10765412.PDF">http://www.laeger.dk/portal/pls/portal/!PORTAL.wwpob_page.show?_docname=10765412.PDF</a></td>
<td>Peter K. Estrup, Tel: 7841 3987</td>
<td><a href="mailto:mette.kramer@livstilregionh.dk">mette.kramer@livstilregionh.dk</a></td>
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<td>Det Nationale Diabetesregister</td>
<td>Diabetes register</td>
<td>1996-2006</td>
<td>Scientific Research</td>
<td>Dinesen Skorpen, Tlf.: 3268 5142, <a href="mailto:mebp@ssi.dk">mebp@ssi.dk</a></td>
<td><a href="http://www.ssi.dk/Sundhedsdataogit/Registre%20og%20kliniske%20databaser">http://www.ssi.dk/Sundhedsdataogit/Registre%20og%20kliniske%20databaser</a></td>
<td>KCKS, West: Mette Kramer Pedersen</td>
<td><a href="mailto:mette.kramer@livstilregionh.dk">mette.kramer@livstilregionh.dk</a></td>
<td>Tel: +45 3545-1128</td>
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<td>Det nationale skizofrenidatabase</td>
<td>The national schizophrenia database</td>
<td>2005-2006</td>
<td>Clinical quality</td>
<td>Region H, KCKS-Vest</td>
<td>Anne Nakano, KCKS-West, E-mail: <a href="mailto:annenakano@rm.dk">annenakano@rm.dk</a></td>
<td><a href="http://www.unidatabase.dk/">http://www.unidatabase.dk/</a></td>
<td>Region H - Kompetencecenter Syd</td>
<td><a href="mailto:Selskabssekretariat@nephrology.dk">Selskabssekretariat@nephrology.dk</a></td>
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| 51  | Blood     | Landsdækkende kliniske databaser / National Clinical Database | National Clinical Database | Clinical vein database | Region H - Det nationale Indikationsprojekt | katrine.abletitrup.nielsen@rmm.dk | https://www.regnorh.dk/landshals/rapporter/rapporter/rapporter.pdf
| 52  | Condition | Respiratory       | Chronic obstructive pulmonary disease | ? | Clinical quality | Region H - Det nationale Indikationsprojekt | kristen.vinding.kirsten.laiva@regionh.dk, thor.schmitz.thor.schmidt@regionh.dk | http://www.kdksvest.dk/landshals/rapporter/rapporter/rapporter.pdf
| 53  | Specific Procedure | Elderly | Landsdækkende database for Geriatrics | Nationwide database of Geriatrics | GEB | Clinical quality | Region H - Det nationale Indikationsprojekt | jeanne.duus.johansen@regionh.dk, monika.madsen.01@regionh.dk | http://www.kdksvest.dk/landshals/rapporter/rapporter/rapporter.pdf
| 54  | Condition | Landsdækkende kliniske databaser / National Clinical Database | Landsdækkende Klinisk Database for Kontaktkvalitet | Nationwide Clinical Database of Contact Allergy | Scientific Research | Region H - Det nationale Indikationsprojekt | jeanne.duus.johansen@regionh.dk, monika.madsen.01@regionh.dk | http://www.kdksvest.dk/landshals/rapporter/rapporter/rapporter.pdf
| 55  | Cardio    | Landsdækkende kliniske databaser / National Clinical Database | Landegjældet/Karbase / Karbase register | The Danish Vascular Registry | 1903-00 | Clinical quality | Region H - Det nationale Indikationsprojekt | nikolaj.eldrup@ki.au.dk, kathrine.roos.prechtzanima@regionh.dk | http://www.kdksvest.dk/landshals/rapporter/rapporter/rapporter.pdf
| 56  | Cancer    | Landsdækkende kliniske databaser / National Clinical Database | Monitoring af pakkeforløb for kraft | Monitoring of pathways for cancer | April 2010 - > | Quality Assessment | Tlf.: 78 45 09 50, E-mail: slekjeny.dcr@gmail.com | http://www.uofdatabase.dk/udskiftetetfinal.pdf
| 57  | Specific Procedure | Men | Landsdækkende kliniske databaser / National Clinical Database | Organ donations database | Organ Donation Database | April 2010 - > | Quality Assessment | Tlf.: 78 45 09 50, E-mail: slekjeny.dcr@gmail.com | http://www.uofdatabase.dk/udskiftetetfinal.pdf
| 58  | Cancer,Men | Landsdækkende kliniske databaser / National Clinical Database | Danish Penis Cancer Committee | UOF-DAPREC | Clinical quality | Danish Regions | anne.nakano@stab.rm.dk | http://www.uofdatabase.dk/udskiftetetfinal.pdf
| 59  | Prostate,Men | Landsdækkende kliniske databaser / National Clinical Database | Prostas register | Danish Prostate Cancer Committee | UOF-DAPROCA | Clinical quality | Danish Regions | anne.nakano@stab.rm.dk | http://www.uofdatabase.dk/udskiftetetfinal.pdf
| 60  | Cancer, Prostate, Men | Landsdækkende kliniske databaser / National Clinical Database | Prostata register | Danish Prostate Cancer Committee | UOF-DAPROCA | Clinical quality | Danish Regions | anne.nakano@stab.rm.dk | http://www.uofdatabase.dk/udskiftetetfinal.pdf
| 61  | Biobank   | Landsdækkende kliniske databaser / National Clinical Database | The Tissue Register | VAR | 2004-00 | Scientific Research | Statens Serum Institut | linda.slaaby.kongeslev@regionh.dk, tlf.: 3298 5138 | http://www.uofdatabase.dk/udskiftetetfinal.pdf
| 62  | Cancer    | Landsdækkende kliniske databaser / National Clinical Database | Danish Urological Cancer Group | UoF | Clinical quality | Danish Regions | anne.nakano@stab.rm.dk | http://www.uofdatabase.dk/udskiftetetfinal.pdf
| 64  | Cancer, Men | Landsdækkende kliniske databaser / National Clinical Database | Danish Cancer of the testis Committee | UOF-DATECA | Clinical quality | Danish Regions | anne.nakano@stab.rm.dk | http://www.uofdatabase.dk/udskiftetetfinal.pdf
| 65  | Condition | National Indikator Project NIP | Akut move-tarm kirurgi database | NIP | Treatment quality | Region H - Det nationale Indikationsprojekt | hanna.joensen@regionh.dk, tlf.: 3268 5133 | http://www.uofdatabase.dk/udskiftetetfinal.pdf
| 66  | Patient information | Patient information | Ventelister ventefoto.dk | Waiting Time | | | | | http://www.laeger.dk/portal/pls/portagautreg/docname=10765412.PDF
| 67  | Admin / Case Registration, Hospital | Saagbehandling | Administration af udfleveringsvedkærer | | | | | | http://www.laeger.dk/portal/pls/portagautreg/docname=10765412.PDF
| 68  | Admin / Case Registration, Hospital | Saagbehandling | Authorization Register | AUT | Administrative | Statens Serum Institut | hanna.joensen@regionh.dk, tlf.: 3268 5133, hajen@sssi.dk | http://www.laeger.dk/portal/pls/portagautreg/docname=10765412.PDF
| 69  | Admin / Case Registration, Hospital | Saagbehandling | Ordinationer af kopipligtige lægemidler | | | | | | http://www.laeger.dk/portal/pls/portagautreg/docname=10765412.PDF
| 70  | Orthopaedic | Saagbehandling | Movement Register | Administrative | | | | | http://www.laeger.dk/portal/pls/portagautreg/docname=10765412.PDF
| 71  | Statistik | Saagbehandling | Danmarks Statistik | Danmarks Statistik | | | | | http://www.laeger.dk/portal/pls/portagautreg/docname=10765412.PDF
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<td>72</td>
<td>Hospital</td>
<td>National Patient Register - Activity on diagnosis group</td>
<td>LPR</td>
<td>Administrative</td>
<td>Kristian Nielsen, Tel: 3268 5135, <a href="mailto:km@ssi.dk">km@ssi.dk</a>, Erik Viladsten, Tel: 3268 5131, <a href="mailto:erv@ssi.dk">erv@ssi.dk</a></td>
<td><a href="http://www.ssi.dk/Sundhedsdataogit/Re">http://www.ssi.dk/Sundhedsdataogit/Re</a></td>
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<td>73</td>
<td>Hospital</td>
<td>National Patient Register - Activity on diagnosis level</td>
<td>LPR</td>
<td>Administrative</td>
<td>Kristian Nielsen, Tel: 3268 5135, <a href="mailto:km@ssi.dk">km@ssi.dk</a>, Erik Viladsten, Tel: 3268 5131, <a href="mailto:erv@ssi.dk">erv@ssi.dk</a></td>
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<td>74</td>
<td>Hospital</td>
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<td>LPR</td>
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<td>Kristian Nielsen, Tel: 3268 5135, <a href="mailto:km@ssi.dk">km@ssi.dk</a>, Erik Viladsten, Tel: 3268 5131, <a href="mailto:erv@ssi.dk">erv@ssi.dk</a></td>
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<td>LPR</td>
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<td>Kristian Nielsen, Tel: 3268 5135, <a href="mailto:km@ssi.dk">km@ssi.dk</a>, Erik Viladsten, Tel: 3268 5131, <a href="mailto:erv@ssi.dk">erv@ssi.dk</a></td>
<td><a href="http://www.ssi.dk/Sundhedsdataogit/Re">http://www.ssi.dk/Sundhedsdataogit/Re</a></td>
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<td>Admin, hospital</td>
<td>National Patient Register - GP Register (doctors, dentists, fysiotherapists etc.)</td>
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<td>Administrative</td>
<td>Christian Theodor Ulrich, Tlf.: 3268 9065, <a href="mailto:cth@ssi.dk">cth@ssi.dk</a></td>
<td><a href="http://www.ssi.dk/Sundhedsdataogit/Re">http://www.ssi.dk/Sundhedsdataogit/Re</a></td>
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<td>Admin, Hospital</td>
<td>National Patient Register - Regional Accounts &amp; finances</td>
<td>DUSAS</td>
<td>Administrative</td>
<td>Milan Fajber, Tlf:3268 5143, <a href="mailto:mifa@ssi.dk">mifa@ssi.dk</a></td>
<td><a href="http://www.ssi.dk/Sundhedsdataogit/Re">http://www.ssi.dk/Sundhedsdataogit/Re</a></td>
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<td>Admin, Hospital</td>
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<td>Milan Fajber, Tlf:3268 5143, <a href="mailto:mifa@ssi.dk">mifa@ssi.dk</a></td>
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<td>Milan Fajber, Tlf:3268 5143, <a href="mailto:mifa@ssi.dk">mifa@ssi.dk</a></td>
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<td>Reflecting Registers</td>
<td>National Patient Register - Bivikrningsovervågning (Marg)</td>
<td>DPSD</td>
<td>Administrative</td>
<td>Milan Fajber, Tlf:3268 5143, <a href="mailto:mifa@ssi.dk">mifa@ssi.dk</a></td>
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<td>Administrative</td>
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<td>Administrative</td>
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<td>Treatment quality</td>
<td>National Patient Register - Waiting time in Danish pharmacies</td>
<td>DPSD</td>
<td>Scientific Research</td>
<td>Milan Fajber, Tlf:3268 5143, <a href="mailto:mifa@ssi.dk">mifa@ssi.dk</a></td>
<td><a href="http://www.ssi.dk/Sundhedsdataogit/Re">http://www.ssi.dk/Sundhedsdataogit/Re</a></td>
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<td>Psychiatry</td>
<td>National Patient Register - DIPSD (Danes treated at foreign hospitals)</td>
<td>DPSD</td>
<td>Scientific Research</td>
<td>Milan Fajber, Tlf:3268 5143, <a href="mailto:mifa@ssi.dk">mifa@ssi.dk</a></td>
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<td>Statens Serum Institut</td>
<td>Claudia Ranneries, Tlf: 32685512, <a href="mailto:crwa@ssi.dk">crwa@ssi.dk</a></td>
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<td>Scientific Research</td>
<td>Statens Serum Institut</td>
<td>Maya Christel Miller, Tlf: 3268 5152, <a href="mailto:mediche@ssi.dk">mediche@ssi.dk</a></td>
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<td>Medicines Register</td>
<td>Sundhedsovervågning</td>
<td>LSR 1984-ge</td>
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<td>Administrative</td>
<td>Statens Serum Institut</td>
<td>Tlf: 3266 5125, <a href="mailto:medicinr@ssi.dk">medicinr@ssi.dk</a></td>
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<td>94</td>
<td>Landsdækkende register for Patologi</td>
<td>Sundhedsovervågning</td>
<td>LRP 1970-ge, but not covering the whole country until 1997-ge</td>
<td>Pathology register</td>
<td>Scientific Research</td>
<td>Center for Ulykkeforstudier</td>
<td>Bjarne Laursen or Hanne Møller, 65507777</td>
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<td>The Accident Register</td>
<td>Accident</td>
<td>1990-ge</td>
<td></td>
<td>Scientific Research</td>
<td>The Accident Register</td>
<td>Christian Theodor Ulrich, Tlf: 3268 9065,<a href="mailto:chtu@ssi.dk">chtu@ssi.dk</a></td>
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<td>96</td>
<td>Medical Birth Register</td>
<td>Birth, Child</td>
<td>MFR 1923-1996. After 1995 through local person registers</td>
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<td>Statens Serum Institut</td>
<td>Christian Theodor Ulrich, Tlf: 3266 9055, <a href="mailto:chtu@ssi.dk">chtu@ssi.dk</a></td>
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<td>97</td>
<td>The Neonatal Screening Biobank PKU</td>
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<td>Cause of Death Register - Stillborn</td>
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<td>DAR 1970-ge</td>
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<td>Statens Serum Institut</td>
<td>Claudia Ranierees, Tlf: 32685512, <a href="mailto:crwa@ssi.dk">crwa@ssi.dk</a></td>
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<td>99</td>
<td>Coercive Psychiatry Register</td>
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<td>SBI 1999-ge</td>
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<td>Emil Nygaard Jørgensen, <a href="mailto:tvang@ssi.dk">tvang@ssi.dk</a>, Tlf: 2230 7904</td>
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<td>100</td>
<td>The Health Agency's Central Dental Register (SCOR)</td>
<td>Sundhedsovervågning</td>
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<td>Alcohol treatment register</td>
<td>Therapy, Addiction</td>
<td>NAB 2005-ge</td>
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<td>Statens Serum Institut</td>
<td>Claudia Ranneries, Tlf: 32685512, <a href="mailto:crwa@ssi.dk">crwa@ssi.dk</a></td>
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<td>102</td>
<td>Blood spots from all newborn Danes since 1976</td>
<td>Birth, child</td>
<td>Blood spots from all newborn Danes since 1976</td>
<td></td>
<td>Scientific Research</td>
<td>Denmark Biobank Registry</td>
<td>Tel: 3268 5199 / 3268 9163, <a href="mailto:mail@nationalbiobank.dk">mail@nationalbiobank.dk</a>, Dahanca Secretariat, +45 7846 2620, <a href="mailto:DAHANCA@oncology.dk">DAHANCA@oncology.dk</a></td>
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<td>The Child Database (Children's health) - First living year</td>
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<td>Statens Serum Institut</td>
<td>Thomas Tjørnelund Nielsen, Tlf: 3266 5162, <a href="mailto:thtn@ssi.dk">thtn@ssi.dk</a></td>
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<td>The Child Database (Children's height) - Early and late primary school (BMI, height &amp; weight)</td>
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<td>Thomas Tjørnelund Nielsen, Tlf: 3266 5162, <a href="mailto:thtn@ssi.dk">thtn@ssi.dk</a></td>
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<td>Administrative</td>
<td>Statens Serum Institut</td>
<td>Maya Christel Miller, Tlf: 3268 5152, <a href="mailto:mediche@ssi.dk">mediche@ssi.dk</a></td>
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<td>Danish Head and Neck Cancer Group</td>
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<td>Clinical quality</td>
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<td>Voleen, Susanne Srenkr, <a href="mailto:Susanne.Srenkaer@regioh.dk">Susanne.Srenkaer@regioh.dk</a></td>
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<td>Scientific</td>
<td>Lisbet Rosenkrantz, helmed, Klinik forskningslaboratorium (KKG), Sofia Kyndesen, <a href="mailto:sofia.m.johnsen@regionh.dk">sofia.m.johnsen@regionh.dk</a></td>
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<td>Scientific Research</td>
<td>Italian Institute for Folkesundhed</td>
<td><a href="mailto:Lena.Konig@regionh.dk">Lena.Konig@regionh.dk</a></td>
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<td>Danish Regions</td>
<td>Peter Johannsen, Tlf 3545 6702 <a href="mailto:peter.johannsen@regionh.dk">peter.johannsen@regionh.dk</a></td>
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<td>Femoral fractures</td>
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<td>Niels Wisbech Pedersen, Nils W. <a href="mailto:Pedersen@rsyd.dk">Pedersen@rsyd.dk</a>, Helen Madsen Rasmussen, <a href="mailto:helen@cpp.dk">helen@cpp.dk</a>, Softa Kjendes, <a href="mailto:sofia.m.jin@slaeb.dk">sofia.m.jin@slaeb.dk</a>, <a href="mailto:oeller.kjendes@regionh.dk">oeller.kjendes@regionh.dk</a></td>
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<td>Hospital usage - Population after person group, area, key figures, age and gender</td>
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<td>Indlæggelser, sengedage og indlagte patienter efter område, alder og køn</td>
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<td>2006-2013</td>
<td>Scientific Research</td>
<td>Open</td>
<td>Index for ambulant treatments of children after the family's education, age and gender</td>
<td>Indeks for ambulante behandlinger af børn efter familiens uddannelse, alder og køn</td>
<td>AMBP06</td>
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## List of Genome Research Centers

<table>
<thead>
<tr>
<th>Institute</th>
<th>Abbreviation</th>
<th>Formed</th>
<th>Website</th>
<th>Institutional support</th>
<th>Person</th>
</tr>
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<tbody>
<tr>
<td>Center for Biological Sequence Analysis</td>
<td>CBS</td>
<td>1993</td>
<td><a href="http://www.cbs.dtu.dk/">http://www.cbs.dtu.dk/</a></td>
<td>DTU</td>
<td>Ole Lund</td>
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<tr>
<td>Center for Plant-Microbe Symbiosis</td>
<td>CPMS</td>
<td></td>
<td><a href="http://www.natlab.dtu.dk">http://www.natlab.dtu.dk</a></td>
<td>RISØ National Laboratory</td>
<td>Henriette Giese</td>
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<tr>
<td>Center for Molecular Plant Physiology</td>
<td>PlaCe</td>
<td></td>
<td><a href="http://www.ku.dk/">http://www.ku.dk/</a></td>
<td>The Royal Veterinary and Agricultural University.</td>
<td>Birger Lindberg Møller</td>
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<tr>
<td>Center for Experimental Bio Informatics</td>
<td>CEBI</td>
<td></td>
<td><a href="http://www.cebi.sdu.dk/">www.cebi.sdu.dk/</a></td>
<td>University of Southern Denmark</td>
<td>Matthias Mann</td>
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<tr>
<td>Center for GeoGenetics</td>
<td>-</td>
<td></td>
<td><a href="http://geogenetics.ku.dk/">geogenetics.ku.dk/</a></td>
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<td>Eske Willerslev</td>
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<tr>
<td>Centre for Gene Regulation and Plasticity of Neuro-endocrine Network</td>
<td>-</td>
<td>2001</td>
<td><a href="http://www.ku.dk/">http://www.ku.dk/</a></td>
<td>University of Copenhagen</td>
<td>Niels Tommerup, <a href="mailto:tommersup@imbg.ku.dk">tommersup@imbg.ku.dk</a></td>
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<tr>
<td>Wilhelm Johannsen Centre for Functional Genome Research</td>
<td>WJC</td>
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<td><a href="http://www.wjc.ku.dk/">http://www.wjc.ku.dk/</a></td>
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<tr>
<td>Centre for Epigenetics</td>
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<tr>
<td>Centre for mRNP Biogenesis and Metabolism</td>
<td></td>
<td></td>
<td>mnrp.au.dk</td>
<td>Aarhus University</td>
<td>Torben Heick Jensen</td>
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