INSPIRE Compliance of Public Health Information
A Danish Case Study
Lyseen, Anders Knørr; Hansen, Henning Sten

Published in:
International Journal of Spatial Data Infrastructures Research

DOI (link to publication from Publisher):
10.2902/1725-0463.2015.10.art4

Publication date:
2015

Link to publication from Aalborg University

Citation for published version (APA):

General rights
Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

? Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
? You may not further distribute the material or use it for any profit-making activity or commercial gain
? You may freely distribute the URL identifying the publication in the public portal.

Take down policy
If you believe that this document breaches copyright please contact us at vbn@aub.aau.dk providing details, and we will remove access to the work immediately and investigate your claim.
INSPIRE Compliance of Public Health Information – A Danish Case Study*

Anders K. Lyseen¹, Henning Sten Hansen²

¹,²Department of Development and Planning, Aalborg University, Denmark, alyseen@plan.aau.dk ; hsh@plan.aau.dk

Abstract

Geographical information systems have become important to research, planning, commercial businesses, and health organisations in the public and private sectors. Data management and sharing are advantageous considering that repeating tasks is costly. The existence of several versions of the ‘same’ dataset raises concerns over data reliability and authority. Digitisation, which largely involves spatial information, is one approach for sharing data. Thus, digitisation is a vital part of the Danish e-government strategy. A well-functioning spatial data infrastructure (SDI) is an important prerequisite for e-governance. Implementation of the INSPIRE Directive has placed emphasis on SDI within key ministries and has resulted in several national services with free access to spatial data. However, until now, public health information has not been a part of the Danish SDI. In Denmark, several organisations have created independent public health datasets, and the infrastructure of the data is undocumented. Obtaining an overview of the available health data suitable for spatial applications is not easy. Most public health data do not have any spatial references, but it should be linked to features with a spatial reference, for example, administrative units or addresses. According to Danish legislation, health information is private, which imposes great limitations on the use of health data. Human health information should not be isolated, which is more or less the situation today, but rather seamlessly combined with other data. The aim of the current research is to identify available public health data in Denmark, including links to spatially referenced features, and to analyse its compliance with

*This work is licensed under the Creative Commons Attribution-Non commercial Works 3.0 License. To view a copy of this license, visit http://creativecommons.org/licenses/by-nc-nd/3.0/ or send a letter to Creative Commons, 543 Howard Street, 5th Floor, San Francisco, California, 94105, USA.

DOI: 10.2902/1725-0463.2015.10.art4
the principles of the INSPIRE Directive. The INSPIRE Directive includes the theme of human health and safety, and it is the basis for identifying available health data.

**Keywords:** Health, Spatial Data Infrastructure, INSPIRE, Open Data

1. **INTRODUCTION**

Geographical information systems have become important in research, planning, commercial business, and health organisations in the public and private sectors. Geography is important in understanding the dynamics of health, and the location or spatial reference is often the key to joining many health data and spatial datasets (Boulos, 2005). Epidemiologists and medical geographers have applied the spatial dimension to health data to understand the causes and spread of diseases. The earliest examples date back to Finke and Seaman in the 1790s (Barrett, 2000). Presumably, the most famous example is the mapping of cholera in 1854 (Snow, 1855). Human health is influenced by the environment in which the person lives and by socioeconomic factors. The spread of disease and other threats to health (e.g., air pollution) do not follow administrative borders. Human health information should not be isolated from spatial datasets, as is occurring today. Hence, there is a need to join health and environment datasets (Thompson et al, 2009).

Most countries face increases in the expenditures for healthcare, which are largely a result of an ageing population and chronic diseases associated with particular lifestyles. An effective primary healthcare system plays an important role in managing the increasing demands on the health care system. For the healthcare system to be effective, collaboration through sharing of health data and data on accessibility of health services for targeting limited resources are required (Thompson et al, 2009). An efficient spatial data infrastructure (SDI) would enable effective access and use of health datasets and would possibly improve the quality and efficiency of the healthcare system (Murdoch and Detsky, 2013). Data management and sharing have many benefits considering that we cannot afford to repeat tasks due to limited resources. Multiple versions of the ‘same’ dataset raise concerns regarding the reliability and authority of datasets.

Digitisation of public spatial data is on the agenda for many governments, and each country is developing their own national SDIs (EDINA). Commonly, national SDIs focus on traditional spatial data, such as addresses, property information, spatial planning, remote sensing data and environmental data. However, at best, spatial health data have a very limited implementation in national SDIs; Denmark has only a few health datasets available (Danish Geodata Agency). There are several
international databases that distribute spatial health data, i.e., Worldmapper, those listed in (Mathys and Boulos, 2011), the World Health Organisation (World Health Organisation (1)), HIVMapper (HIVMapper) and HIV Spatial Data Repository (HIV Spatial Data Repository). Only a few countries have or are developing spatial data infrastructures that include health data. In the United Kingdom, an environment and health atlas (SAHSU) has been published. Additionally, the SDI Go-Geo (EDINA) delivers metadata, spatial data and interactive mapping to medical researchers, public health officials and the general public (Mathys and Boulos, 2011). New Mexico has developed a web portal to integrate environmental information and health information (EPHT). In Victoria, Australia, spatial data access and management is a priority. An SDI to increase and strengthen effective collaboration within health projects and add benefits through increased use of under-used data is being developed (Thompson et al, 2009).

Health data include some of the most personal and private information on people. However, patient-identifiable data are critical to medical research considering that updating, linking and validating data are impossible without identifiable data, and the implementation of potential confounders in the analysis is difficult (Haynes et al, 2007). Addresses are needed for analysis and spatial aggregation of data. Spatial aggregation is a means of preserving confidentiality while maintaining an acceptable level of data usefulness (Boulos et al, 2009). The privacy concerns additionally challenge health researchers due to the expensive and time-consuming methods to secure data anonymity or confidentiality. Ultimately, there is always a trade-off between privacy concerns and the types and accuracy of possible spatial analyses of health (Boulos et al, 2009).

Within the healthcare sector, there are vast amounts of data, but the application of spatial information in the healthcare sector has been ad hoc and uncoordinated (Thompson et al, 2009). The large number of agencies involved in healthcare systems requires common data systems to coordinate the sharing of datasets efficiently (Thompson et al, 2009). The data assembly at the Statens Serum Institute (SSI) in Denmark has combined previously independent data administrations and centralised the administration of the central health care registers in Denmark. However, obtaining an overview of available health data suitable for spatial applications is not easy. Most public health data do not have any spatial references, but it needs to be linked to features with a spatial reference, for example, administrative units or addresses.

Therefore, the aim of the current research is to identify available health data in Denmark, including links to spatially referenced features, and to analyse its compliance with the principles of the INSPIRE Directive.

The paper begins with a description of the Danish SDI and the implementation of the INSPIRE Directive in Denmark. Then, the Danish health data infrastructure is
described, along with initiatives for the development of the data infrastructure in the Danish healthcare system. The national registers, spatial web services, and their relationships are introduced. The compliance of health data with the INSPIRE Directive is analysed. Finally, the issues related to the compliance and the inevitable privacy concerns of health data are discussed.

2. THE DANISH SPATIAL DATA INFRASTRUCTURE

The Danish national spatial data infrastructure is a common foundation for the management of geographical information and digital administration in Denmark (Hansen et al. 2011). A well-functioning spatial data infrastructure is an important prerequisite for e-governance. The implementation of the INSPIRE Directive has emphasised SDI within key ministries and has resulted in several national services with free and easy access to spatial data on the environment, spatial planning, addresses, cadastral maps, and topography. However, until now, public health information has not been a part of the Danish national SDI. In 2008, the Danish government enacted The Act on Infrastructure for Geographic Information as a response to the European INSPIRE Directive. The act ensures the implementation of the INSPIRE Directive in Denmark and that the common framework can be applied widely in the national geographical data infrastructure. The Danish spatial data infrastructure follows the basic principles of INSPIRE and establishes common rules, conditions and guidelines for the data, services, technologies, metadata, and the organisation (Danish Ministry of the Environment, 2008). The Danish infrastructure for spatial information consists of data and services through web portals or standardised services, such as Web Map Services (WMS) and Web Feature Services (WFS). A web-based portal publishes data and metadata such that users have one place to search and access the data (Danish Geodata Agency, 2014). For a dataset to be a part of the Danish spatial data infrastructure, it must be digital, nationwide and nationally applicable, and statutory (Danish Ministry of the Environment, 2008).

In 2011, The Agency for Digitisation was established, and the national e-government strategy accelerated the process of modernising Danish society (Danish Agency for Digitisation, 2011). The digital-based ambitions are described in the Danish e-government strategy of 2011-2015 (Danish Agency for Digitisation, 2011). The government, municipalities and regions included in the strategy should increase the momentum of digitisation in the public sector. Spatial information and the associated infrastructure play an important role in delivering data for public administration. One of the initiatives is common basic data (Danish Agency for Digitisation, 2012) for all public authorities. Since 2013, spatial and register data have been freely available for the public (Hansen et al., 2013). The strategies program for basic data are directly based on the principles of the INSPIRE Directive to ensure consistency with INSPIRE in the development of the national infrastructure for geographical information and the digital public administration.
INSPIRE also contributes to the coherence and exchange of data across public authorities using international standards, including INSPIRE. Data must comply with the INSPIRE principles to be included in the Danish SDI and INSPIRE.

The principles of the INSPIRE Directive are also utilised as a basis for the development of non-spatial public data collections and the general digital infrastructure in Denmark.

3. HEALTH DATA INFRASTRUCTURE

In 2012, the important national health data at SSI was consolidated to ensure equal and transparent conditions for the use of data and to improve the data quality and sharing for health professionals and researchers. The role of SSI is to gather, analyse and disseminate data. Following the national e-government strategy of 2011-2015 (Danish Agency for Digitisation, 2011), a national strategy for the Digitisation of the Danish Healthcare Sector 2013-2017 was developed. One of the five main initiatives is ‘better use of data’ (Danish Government et al, 2013). This strategy should create a basis for the affordable maintenance of health data, collaboration of information technology across the health sector, and improved quality of health data through ensuring a reliable link between the local health departments and the national registers (Danish Government et al, 2013). The strategy facilitates the management and sharing of health data through a common infrastructure and standards for data, interfaces and services. However, the national strategy for Digitisation of the Danish Healthcare Sector 2013-2017 does not mention INSPIRE or the promotion of spatial applications of health data.

The INSPIRE Directive includes the theme of human health and safety (INSPIRE Thematic Working Group Human Health and Safety, 2011), defined as ‘The geographical distribution of dominance of pathologies, information indicating the effect on health or well-being of humans linked directly or indirectly to the quality of the environment’. The INSPIRE Directive on human health and safety covers a range of data on diseases and health-related problems, as well as other indicators of health effects that are linked directly or indirectly to the environment. The theme of human health and safety involves health conditions of individuals and the population related to the INSPIRE theme population distribution – demography (INSPIRE Thematic Working Group Population Distribution, 2012). The characteristics of a population at a relevant spatial scale are important for analysing human health. The international classification of disease and related health problems (ICD) (World Health Organisation) are used to categorise disease, health-related conditions and external causes of disease and injury within the INSPIRE Directive. Diseases, injuries and accident data are expressed as raw incidence, prevalence or mortality rates under the INSPIRE Directive. Health data can be stratified by gender, age, socioeconomic indicators, or living conditions.
4. DANISH REGISTERS AND SPATIAL WEB SERVICES

Spatial enabling public registers require a common key attribute (Hansen, 2001). The address is an important and unambiguous database key in many private and public registers in Denmark, and all Danish addresses have a spatial reference. The address is easily recognisable and is used to locate residences in the Building and House Register (BBR) and the Central Business Register (CVR). Addresses are also registered in the Civil Person Register (CPR) (Pedersen, 2011), which contains information on individuals in Denmark. CPR is key for linking health data (Bjerregaard and Larsen, 2011), social data, labour market data (Petersson et al, 2011) and education data (Jensen and Rasmussen, 2011). CPR contains addresses that can join a spatially referenced address dataset and can thereby establish a relation between health data and spatial data on, for example, pollution in the Danish Natural Environment portal. All companies, institutions, and public service providers are registered in the CVR and are uniquely identified through the CVR number. The CVR also has information on addresses and industrial classifications. CPR, CVR, BBR, the Property Register (ESR) and the Cadastre Register are part of the Basic Data programme in Denmark.

Statistics Denmark is the national agency for statistical data, and the data are obtained from national public registers. The statistical data are output from individual data aggregated over administrative units, such as parishes, municipalities, regions or the entire country. Additionally, data may be aggregated over miscellaneous spatial units or the Danish National Grid. Aggregation is limited by enforced restrictions to ensure the confidentiality and privacy of individuals. The restrictions enforced by Statistics Denmark require that persons are not identifiable in the data. Therefore, the minimum number of persons or households in an aggregation is variable, depending on the type of data. However, threshold values of a minimum of 50 properties or 100 persons within each spatial unit are often required.

Geodata-info is the national counterpart to the INSPIRE portals that aims to search and discover spatial datasets and associated metadata in Denmark (Danish Geodata Agency). Figure 1 presents the associations between the spatial data repositories, the spatial reference data, data keys, national basic data registers, national health registers and Danish statistics data. Through data keys and spatial references, all the data sources can be related.

In Denmark, the Statens Serum Institute (SSI) maintains the health data registers. The National Institute of Public health (SIF) maintains a few clinical registers and
conducts a national health survey every three years. Table 1 lists registers that contain health data.

**Figure 1: The Association between National Registers through their Key Attributes and the Spatial Reference from Spatial Web Services.**
Table 1: List of Health Registers in Denmark and the Responsible Institution.

<table>
<thead>
<tr>
<th>Health Registers</th>
<th>Responsible authority</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Danish Pathology Register</td>
<td>SSI</td>
</tr>
<tr>
<td>- 51 clinical registers</td>
<td>SSI &amp; SIF</td>
</tr>
<tr>
<td>Cause of death register</td>
<td>SSI</td>
</tr>
<tr>
<td>National Patient Register</td>
<td>SSI</td>
</tr>
<tr>
<td>- Birth and fertility register</td>
<td>SSI</td>
</tr>
<tr>
<td>- Psychiatric Register</td>
<td>SSI</td>
</tr>
<tr>
<td>The Children’s Database</td>
<td>SSI</td>
</tr>
<tr>
<td>The Conscription Register</td>
<td>SSI</td>
</tr>
<tr>
<td>The National Health Insurance Register</td>
<td>SSI</td>
</tr>
<tr>
<td>Rehabilitation Register</td>
<td>SSI</td>
</tr>
<tr>
<td>Health Service Provider Register</td>
<td>SSI</td>
</tr>
<tr>
<td>Central Business Register (CVR)</td>
<td>SSI</td>
</tr>
<tr>
<td>Register of Medicinal Product Statistics</td>
<td>SSI</td>
</tr>
<tr>
<td>Register on Drug Abusers in Treatment</td>
<td>SSI</td>
</tr>
<tr>
<td>The National Health Profile</td>
<td>SIF</td>
</tr>
</tbody>
</table>

All of the national registers maintained at SSI and SIF contain a personal identification number (CPR number) such that all registers can be combined (Pedersen, 2011). The CPR number also provides an opportunity to geocode the data at the address level to support further spatial analysis (e.g., Storgaard et al., 2013). Data from the National Health Profile are based on addresses and are aggregated at the municipality level; the data are freely available from a web portal. The National Health Profile data can be geo-referenced through a polygon feature.
dataset (e.g., administrative boundaries) from the Danish spatial geodata portal, as presented in Figure 2.

**Figure 2: The Process of Geocoding Health Data via the CPR Register and then Spatially Aggregating the Health Data into Administrative Units.**

5. IDENTIFICATION OF HEALTH DATA IN DENMARK

The identification of relevant data for the INSPIRE geo-portal is based on the definition in the INSPIRE Directive theme of human health and safety. To identify possible health data, the definition is divided into six groups, and a detailed description follows

5.1. Spatial Distribution of Dominance of Pathologies

In Denmark, 51 clinical databases contain information on the prevalence, incidence and mortality of diseases (Green, 2011). There have been studies on the validity and coverage of these databases (Abildstrøm and Madsen, 2011; Bjerregaard and Larsen, 2011; Gjerstorff, 2011; Green, 2011; Sortso, 2011; Thygesen et al, 2011). In general, the clinical database coverage is large (greater than 95%). The clinical registers contain data that originate from The Danish Pathology Register
Additionally, the Cause of Death Register contains information on all deaths in Denmark. The Cause of Death Register is available in aggregated form through the INSPIRE Geoportal. In addition to the clinical registers, The National Institute of Public Health conducts a national health profile on 5% of the population every three years to determine the rate of sickness and specific diseases (Christensen et al, 2013).

5.2. Health Indicators

There are several registers in Denmark that provide data on the health conditions of individuals or population samples. The National Children’s Database has information on children’s exposure to smoking, duration of breastfeeding, and heights and weights in the first and 10th years in school. Second, the Conscript Register contains information on the weight and height of (mostly) men at their eligibility test for conscription at approximately the age of 18. The National Health Profile contains information on the percentage of the population that is over- or under-weight. In addition, the population sample contains information on the absence of sickness.

Birth and fertility registers, which include all births in Denmark, are kept at SSI. SSI also maintains the Psychiatric Register, with information on admission, discharge, treatment and diagnosis in psychiatric departments (Mors et al, 2011). The Birth Register and the Psychiatric Register are part of the Danish National Patient Register, which contains information on treatment at hospitals (Lynge et al, 2011).

Data on the use of health services is available from The National Health Insurance Register and the Rehabilitation Register, providing information on the population’s use of health insurance services, i.e., general practitioners, physiotherapists and dentists (Andersen et al, 2011). Statistics Denmark also has information on hospital activity, hospital occupancy rate, home health care and health service use. In the National Health Profile, there is information on the proportion of the population sample that has visited their general practitioner within the last twelve months. Addresses of registered health service providers are included in the Health Service Provider Register and CVR.

The Register of Medicinal Product Statistics (MEDSTAT) contains information on the medicine user, the prescribers of the medicine and the pharmacies distributing the medicine (Kildemoes et al, 2011). The medicine user is identified through the CPR number, and the prescriber and pharmacy are identified through a code. This information can be used to geocode the user, prescribers and pharmacies.
5.3. Indicators of Well-being
The National Health Profile contains information on stress, self-estimated health, physical/mental health, fatigue, headache, pain, discomfort, sleep disturbance, depression and social interactions, which all are indicators of a person’s well-being.

5.4. Quality of the Environment Directly Influencing Health
Air and ground pollution, water quality, noise, the UV index and pollen are phenomena that influence health. These data are part of the INSPIRE theme of human health and safety, atmospheric conditions, environmental monitoring facilities and natural risk zones. Data on the UV index and air pollution are a part of the INSPIRE geoportal. Noise, air and ground pollution data are also available as spatial data from the Danish Natural Environment portal. The UV index and pollen data are available at the Danish Meteorological Institute. Distributions of industries can be extracted from CVR.

5.5. Quality of the Environment Indirectly Influencing Health
The National Health Profile has information on a population’s habits related to alcohol, smoking, diet, physical activity and sedentary behaviour. SSI has a register on the drug abusers in treatment. Distribution of food retailers, fitness centres and sport facilities are extractable from CVR. The locations of green areas are available as spatial data from two web services: Danish Natural Environment Portal and PlansystemDK; the data are already available in the INSPIRE portal.

5.6. Events of Injury and Death
Information on traffic accidents and number of crimes aggregated at the municipality level are available from Statistics Denmark. The National Board of Industrial Injuries and Danish Working Environment Authority keeps a register of work injuries aggregated at the municipality level. The Danish Safety Technology Authority and Danish Emergency Management Agency have information on injuries and deaths caused by electricity, gas, fire and fireworks at the municipality level.

5.7. INSPIRE Compliance of Health Data
Duplicate data registrations, e.g., clinical registers and the Danish Pathology Register and the Birth Register or Psychiatric Register and the National Patient Register, contradict the INSPIRE principle of collecting and storing data only once. Similarly, for injuries and accident data, this information is collected at more than one location. The clinical registers are consistent with the requirements for the Danish SDI because the data are stored electronically, are nationwide and nationally applicable, and are statutory. Data from the National Health Profile represent a sample of the nationwide population, although the data collection is
not statutory. The Conscription Register primarily contains information on the male population, i.e., it is often biased. Similarly, the statutory requirement for providing data for the Children’s Database is rather new, which results in discrepant numbers of records for different municipalities.

The registers that contain the CPR number are subject to severe privacy and confidentiality issues, legally and technically. Data must be anonymised before it is compliant with INSPIRE or any other public data portal. Aggregation of the data into administrative units or the national/European grid systems (as visualised in Figure 2) is a viable option for making the data anonymous. Administrative units or grid systems make the data easily transparent and combinable with other spatial data.

Metadata is a keystone in the INSPIRE Directive to ensure easy access to information. Currently, there is no easy access to metadata on health data in Denmark. Metadata should follow the standards of INSPIRE so it can be included in the INSPIRE Geoportal and the Danish counterpart Geodata-info.

Centralisation of health data at primarily one authority (SSI) is the first step towards improving the organisation of health data in Denmark. SSI plays an important role in the ongoing digitisation process of the Danish health care system. SSI is responsible for the organisation and control of health data. Thus, SSI has initiated the development of IT systems to support efficient and standardised reporting of health data throughout the health care system. The concept is that health data are registered and added to the registers through real-time updates. This ensures that the health data are available for everybody in the health care sector. The flow of health data is presented in Figure 3. Health professionals have dual roles in the system. Professionals first register data on patients and then access information for treatment. The SSI role is to develop and maintain the data and IT systems and to promote the use of health data for research. Data from some health registers is applied at Danish Statistics, where the data are available in aggregated form. The aggregation is by region, municipality, parish or the national grid system; thus, some health data already have a spatial reference. Previously, the administration of health data was split between multiple units with different procedures. Organising the data at SSI has initiated the development of common standards for health data. This organisation will be an improvement that potentially enhances the use of health data.
6. DISCUSSION

Denmark is dedicated to digitising health care systems. As a result, many advanced national registers with person-identifiable health data on the entire population are available. The registers are high quality and accurate, with broad coverage. An efficient public healthcare system is now possible. In addition, researchers are able to perform high-quality analysis on the entire population or selected cohorts and patient groups without time-consuming and expensive data collection. Implementation of health data in the Danish SDI would be a major step
forward in promoting spatial health research because it allows for effective access and use. Moreover, the data could help improve the quality and efficiency of the healthcare system. Digitising the healthcare system is the foundation for good data management and sharing, but a few Danish national registers are still updated manually, leading to multiple data registrations (Danish Government et al, 2013). This duplicity opposes the basic principles of INSPIRE and the Danish digitisation strategy. This issue must be addressed, as it is too expensive to perform the same task twice. Maintaining several versions of the same dataset raises concerns of data reliability and authority.

The national registers in Denmark all hold information, such as CPR numbers and addresses, for simply linkage of registers and spatial datasets through the use of geographical information systems. Therefore, environmental data and health data can be combined in analysing the causes and outcomes of diseases. However, health data and environmental data have very different requirements and restrictions with regard to spatial and privacy relevance. Health data are subject to heavy legal and ethical restrictions. Modifying data to an aggregated form is essential to bypass these restrictions. However, some degree of detail is inevitably lost in the process. Conversely, legal or sensitivity issues do not restrict environmental data, even though the data refer to a person’s activities, e.g., pollution. Health data are based on individuals who are spatially dynamic. Aggregated health data are a momentary representation of the spatial distribution of incidence and prevalence rates. Environmental data are more stationary as it often only changes in the long-term. Environmental data are not a generalisation, in contrast to the aggregated health data. However, environmental data, such as UV and pollen, have continuous extension and fluctuation over a yearly cycle. This type of data is often based on the interpolation between discrete features and average values over several years. People frequently move; thus, a higher update frequency of health data in the SDI is needed. Environmental data, however, changes slowly over long periods and often does not significantly affect the spatial extent over a year.

The rapid development of technology and spatial software over the last decade has important implications for health applications. However, without proper structuring of health data, the preparation of health data for spatial analysis will continue to be tedious and time-consuming work. However, the harmonisation and implementation of health data in compliance with INSPIRE requires a huge amount of work. To overcome this hurdle, an overall policy is required for the implementation, creation of metadata, linkage to spatial data and aggregation of sensitive and confident data.

The current strategy for digitisation of the Danish healthcare system emphasises basic registration through the development of common systems for the many agencies involved and through centralisation of data agencies. As a result, more
experts are involved. With the few entry points to access data, the required work for researchers is minimised significantly. In the digitisation strategy for the healthcare system, there are no initiatives for spatial health data, which is a problem for further implementation. Policies are essential for setting binding agreements; without strict requirements, there is little impetus to develop spatial health data.

Metadata is a keystone for an efficient SDI to support good data management and exchange information. Metadata creation and publication is perceived as tedious and time-consuming; however, without metadata, there is a risk that datasets become redundant. Documentation of Danish health care data is unstructured and is probably mainly a result of the previous administration. Restructuring of the metadata for health is required for consistency and organisation. There are several studies on the validation of registers with health data in Denmark (Abildstrøm and Madsen, 2011; Bjerregaard and Larsen, 2011; Gjerstorff, 2011; Green, 2011; Lyseen and Hansen, 2014; Sortsø, 2011; Thygesen et al, 2011), which could be applied for the creation of metadata information for health datasets.

Health data on the individual level holds detailed information that is subject to concerns over patient confidentiality and data security. There are numerous examples of data security breaches in Denmark in which data containing person-identifiable CPR numbers were hacked or stolen. Strong trust is put into the CPR number in Denmark; thus, the CPR number is powerful. Health registers have sensitive information, and most people would not like their personal medical history to be freely available. All parties involved with health data must ensure the confidentiality of individuals and protect the data both legally and technically.

Patient-identifiable data are critical to medical research: updating, linking and validating data are impossible without person identifiable data, and the implementation of potential confounders in the analysis is difficult (Haynes et al, 2007). There is always a trade-off between the requirements of researchers and privacy concerns, despite the indisputable value of patient-identifiable data. Danish legislation limits the access to individual health information to employees within the sector with relevant needs and to researchers who were granted permission through legal channels. Person-identifiable data cannot be part of INSPIRE, but by making the data anonymous, the data can legally be a part of the national geoportal. Aggregating health data into administrative units or grid systems is a possibility for making the data anonymous. However, the spatial units must contain enough observations such that individual persons or families are not recognisable. Deciding between administrative units or a particular grid size for aggregation is difficult due to the various needs at multiple spatial and temporal scales. However, grid systems have the advantage of remaining the same over time and avoiding the modifiable area unit problem (MAUP) (Openshaw, 1983).
Denmark has progressed in the implementation of INSPIRE annex 1 and 2 data. The next couple of years are devoted to the harmonisation of the many thematic datasets in annex 3, including health data. The continuation of work with applications and the integration of the spatial components of the digital public administration of health data support the possibility of efficiency and increased use in research, public administration and the private sector.

7. CONCLUSION

Denmark has a vast amount of health data in digital databases, but there are several issues that must be addressed before the data are compliant with the INSPIRE principles. The issues relate to duplicate registrations of the same data, and the lack of access to structured metadata. Further efforts to anonymise data are required to ensure the privacy and confidentiality of health data. Spatial aggregation is the key to making the data anonymous, whereas CPR ensures the linkage between the health data and the addresses that serve as the spatial reference. The lack of initiative to include spatial applications of health data on the agenda for the digitisation of health data hinders the implementation of health data in INSPIRE. The issues of spatially aggregated health data and compliancy must be addressed. The harmonisation and implementation of health data in accordance with the INSPIRE Directive are unstructured and slowed by the lack of strategic promotion of spatial health data.

REFERENCES


Danish Agency for Digitisation (2012). Fact Sheet - Basic Data, at http://www.digst.dk/Servicemenu/English/Digitisation/~/media/Files/English/Fact_sheet_BasicData_pdf.pdf [Accessed 8 June 2014].


EDINA. GoGeo, The Place to Discover Geospatial Information and Services for those in Education and Research at http://www.gogeo.ac.uk/gogeo/index.htm [Accessed 8 June 2014].


HIV Spatial Data Repository. Spatial Data Repository at http://www.hivspatialdata.net/ [Accessed 8 June 2014].


