INSPIRE compliance of public health information
– A Danish case study

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Spatial health analysis in more than 200 years

• Epidemiologists and medical geographers has for many years applied the spatial dimension on health data to increase the understanding of disease cause and spread

• Geography is important in understanding the dynamics of health

• Human health is influenced by the environment in which we live
Health is not limited by borders

- The spread of diseases does not follow country borders
- Neither does phenomenon’s influencing peoples health i.e. air pollution
- Human health information should not be isolated

- Development in technologies and spatial software carries great application potential within health
- .... But without proper structuring and information about the health data, preparation of health data for spatial analysis will continue to be tedious and time-consuming work
Spatial HEALTH data infrastructures?

• Digitation of public spatial data is on the agenda for many governments and each country is developing their own national SDIs

• Commonly for the national SDIs is the focus on traditional spatial data such as addresses, property information, spatial planning, remote sensing data and environmental data

• However, spatial health data is only to some degree or not at all part of the national SDIs and Denmark is no exception

• Within the healthcare sector, there are vast amounts of data, but application of spatial information in the healthcare sectors has been ad hoc and uncoordinated
Health data for SDI

- For a dataset to be part of the Danish spatial data infrastructure it have to:
  - exist electronically
  - be nationwide and nationally applicable
  - and the data collection be statutory
The five INSPIRE principles

• Data should be collected only once and kept where it can be maintained most effectively
• It should be possible to combine seamless spatial information from different sources across Europe and share it with many users and applications.
• It should be possible for information collected at one level/scale to be shared with all levels/scales; detailed for thorough investigations, general for strategic purposes.
• Geographic information needed for good governance at all levels should be readily and transparently available.
• Easy to find what geographic information is available, how it can be used to meet a particular need, and under which conditions it can be acquired and used.
The INSPIRE theme Human Health and safety

- **Spatial distribution of dominance of pathologies** – disease prevalence, incidence and mortality
- **Health indicators** – health service use, fertility, medicament use, etc.
- **Indicators of well-being** – stress, fatigue, depression, etc.
- **Quality of the environment directly influencing health** – pollution, noise, etc.
- **Quality of the environment indirectly influencing health** – addictive substances, dietary behaviour, physical activity, etc.
- **Events of injury and death** – road accidents, injuries, etc.
Available health data

• There is huge amounts of information registered about an individual in Denmark

• National health registers:
  • 51 clinical databases
  • Cause of Death Register
  • Birth and fertility registers
  • Psychiatric Register
  • Danish National Patient Register
  • Danish Pathology Register
  • Register on health service use
  • Prescription Register
  • Register on treatment of drug users

• The national health profile (3 year interval)
  • Stress & Depression
  • Physical/Mental health
  • Headache, pain & discomfort
  • Fatigue & sleep disturbance
  • Social interaction
  • Habits related to alcohol, smoking, diet, physical activity and sedentary behaviour

• Datasets with influence on health
  • Air and ground pollution
  • Water quality
  • Noise
  • UV index
  • Pollen
  • Part of other INSPIRE themes and partly integrated already.

• Most public health data does not have any spatial references, but needs to be linked to features with a spatial reference
Linkage of data between registers
Linkage of data between registers.
Available health data

• There is huge amounts of information registered about an individual in Denmark

  National health registers:
  • 51 clinical databases
  • Cause of Death Register
  • Birth and f-
  • ... (Civil Person Register)
  • CPR number
  • Danish Pathology Register
  • Register on health service use
  • Prescription Register
  • Register on treatment of drug users

• The national health profile (3 year interval)
  • Stress & Depression
  • Physical/Mental
  • Head- 
  • Habits related to alcohol, smoking, diet, physical activity and sedentary behaviour

• Datasets with influence on health
  • Air and ground pollution
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INSPIRE compliance

- Obstacles that have to be overcome:
  - Duplicate registration of data contradicts the INSPIRE principle of only collecting data once and store it where it is maintained most effectively
  - having several versions of the same data set always raises questions about reliability, and which data set should be given the authoritative stamp
  - Some registers is biased i.e. predominantly male population sample.
  - The registers containing the CPR-number is subject to severe privacy and confidentiality issues legally and technically.
  - Anonymisation of the data is a must
    - i.e. administrative units or the national/European grid systems
    - the grid systems has the advantage of not changing over time or being subject to the modifiable area unit problem (MAUP)
  - Search on metadata on health data
    - metadata have to be created following the standards in INSPIRE
Privacy and confidentiality issues

• Denmark has a very liberal attitude legally to registers and access hereof
• Health data on individual level holds detailed information that is subject to concerns about patient confidentiality and data security
• Health registers are sensitive information and most people would not like their personal medical history to be freely available
• Ensure confidentiality of individuals and securing data both legally and technically.
• Patient identifiable data are critical to medical research – great value in research and for the public
• There will always be a trade-off between the detail level of data and privacy concerns in spite of the indisputable value of patient identifiable data.
• Person identifiable data cannot be part of INSPIRE
• Aggregation of health data is a possibility for anonymisation of data
Health systems today

• Most countries in the world is facing increases in the expenditures for health
• An effective primary health care system plays an important role in managing the increasing demand pressures on the health care system
• One part in an efficient healthcare system is effective collaboration through sharing of health data and efficiency improvements in data management
• Health registers is of high quality with good validity and high coverage
  • Provides immense possibilities for more efficiency in the public healthcare system
  • For researchers to preform analysis of high quality on the entire population or selected cohorts and patient groups without preceding time-consuming and expensive collection of data.
• In the digitalisation strategy for the healthcare system are their no initiatives for spatial health data, which is lack for the further implementation.
• Policies are essential for setting binding agreements, because without there is little incitement for development of spatial health data
Conclusions

• Development of an efficient spatial data infrastructure (SDI) aims at enabling effective access and use of health datasets, and could be an important way to improve quality and efficiency of healthcare systems

• Harmonisation and implementation of health data in INSPIRE is a huge challenge that requires development of an overall national policy for the implementation, creation of metadata, linkage to spatial data and aggregation of sensitive and confident data for anonymisation purposes
Conclusions

• Denmark has come far in the implementation of INSPIRE annex 1 and 2 data and the next couple of years is devoted for harmonization of the many thematic datasets in annex 3 including the health data

• Continuation of work with application and integration of spatial health data in digital public administration, supports the possibilities there are for efficiency and increased use within research, public administration and in the private sector
Thank You!