



## Vigdis Namtvedt Kvalheim

Access to Confidential Data Through a Data Archive  
- The Norwegian Experience -

*“Data is the single most important component for a science based understanding of society.  
To promote and facilitate access to these data is to promote research”*

(ESFRI, CESSDA-PPP, 2007)

Eurostat Workshop  
Microdata access – new development and a way forward  
Luxembourg, 3 and 4 December 2008



## **Social Sciences depend upon secondary data sources**

Led to

- Development of social science data archives
- Systems of data sharing
- Policies of funding bodies
- Collection of data as a shared resource



## Facts About NSD

### What?

- Established as part of the Research Council of Norway in 1971
- Set up in 2003 as a limited liability company 100% owned by the Norwegian Ministry of Education and Research
- Main funding from
  - Research Council of Norway
  - Ministries
  - EU
  - Universities and colleges

### Why?

- Facilitate empirical research that primarily depends on access to relevant and high quality data

### How?

- Ensure easy access to data and services for the research community
- To provide guidance for researchers and students in the fields of data collection, data analysis, data methodology, protection of privacy and research ethics
- Remove financial, technical, knowledge-based, legal and administrative barriers between users and data resources



Eurostat Workshop, Luxembourg, 3 and 4 December 2008



## OECD Principles and Guidelines for Access

Today, there is a general understanding that data constitute the key element of a functioning research infrastructure, and a recognition that;

People and policies, human resources, capital resources, institutional and legal practice do affect opportunities for more truly comparative research on a wide range of high quality truly European data

Eurostat Workshop, Luxembourg, 3 and 4 December 2008

NSD Norsk samfunnsvitenskapelig datatjeneste

## Role of Data Archives

- Act as honest brokers providing data
- Have expertise in confidentiality and understand the impact of relevant legislation and practice on different types of research
- Argue for access
- Help to build trust in research

Eurostat Workshop, Luxembourg, 3 and 4 December 2008

NSD Norsk samfunnsvitenskapelig datatjeneste

## The Norwegian Experience - collaboration

- Research Council of Norway
  - Funding of existing archives that contains data on individuals, regions, and political and administrative systems
- Data Protection Agency
  - NSD as a broker between the Agency and the scientific community. Today NSD function as Data Protection Official for research
- Statistics Norway
  - Since 1976, a formal agreement on dissemination of data for research purposes. Allowing for extensive use of aggregated and individual data; for instance surveys and register data
- Research Community
  - Close contact with researchers in different scientific fields



Eurostat Workshop, Luxembourg, 3 and 4 December 2008

NSD Norsk samfunnsvitenskapelig datatjeneste

Prosjektoversikt

## Data Protection Official for Research

Review research projects against requirements of the Personal Data Act and the Health Register Act on behalf of 140 research institutions, and on the authority by the Data Protection Agency

Contribute to a climate of trust and legitimacy

Year	Number of notifications
2001	700
2002	800
2003	1000
2004	1500
2005	2000
2006	2000
2007	2000

Eurostat Workshop, Luxembourg, 3 and 4 December 2008

NSD Norsk samfunnsvitenskapelig datatjeneste

## Cooperation with Statistics Norway

### The purpose of the agreement

- To give researchers and students the easiest possible access to the largest possible amount of Statistics Norway's data, without violating the current regulations and without relaxing the protection of individual data

*The term researcher refers to researchers affiliated with a university or college in Norway or abroad, and the institutional sector in Norway.*

### The scope of the agreement

- Aggregated (table) data for municipalities and census-tracts
- Individual data, anonymous from Statistics Norway's sample surveys or other anonymous individual data (persons and establishments)
- Individual data, indirectly identifiable data to be rendered anonymous before dissemination (1997)

Eurostat Workshop, Luxembourg, 3 and 4 December 2008

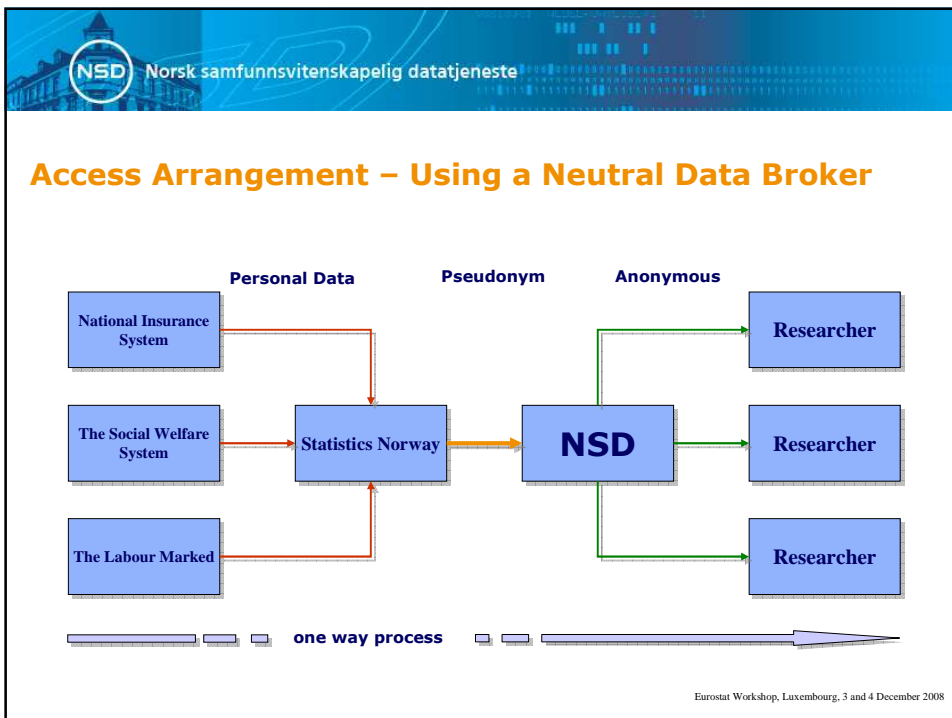
NSD Norsk samfunnsvitenskapelig datatjeneste


## The Data Archive as a Secure Data Access Mechanism

### KIRUT-project, an example of coordinated data management

- Event history database covering eight years
- Data about individuals contact with the welfare system and the labour marked
- 10% yearly up-dated sample of all Norwegians between 16 and 67
- Data from a number of governmental registers
- Merged and made pseudonymous by Statistics Norway
- Transferred to and stored at NSD
- NSD manage access to anonymous and (in special licensed cases) de-identified data for researchers and students
- **Used in hundreds of research and student projects**

Eurostat Workshop, Luxembourg, 3 and 4 December 2008






## Advantages

<h3>Data Producers</h3> <ul style="list-style-type: none"> <li>• Reduce pressure/work load</li> <li>• Supplement direct access as an efficient and cost effective data provision mechanism</li> <li>• Extensive and qualified use</li> <li>• Quality control</li> <li>• Visibility and usability</li> <li>• Support, trust and legitimacy</li> </ul>	<h3>Research Communities</h3> <ul style="list-style-type: none"> <li>• Easy and equal access to rich data resources</li> <li>• Cost and time efficient</li> <li>• Qualified data and support service</li> </ul>
--	---

Eurostat Workshop, Luxembourg, 3 and 4 December 2008



## Data from Registers – Possible Future Solution

### Agreement between Statistics Norway and NSD:

- Statistics Norway and NSD are discussing ways to optimize and secure the services to the research community
- Discussions are based on the Norwegian legal framework
- Building on the experience from more than 30 years of close cooperation
- Transferring pseudonymous or indirectly identifiable personal data from Statistics Norway to NSD based on the KIRUT-experience
- Providing data to researchers and students
  - Anonymous
  - De-identified with approval from the Data protection Official/Data Inspectorate
- Aggregated data to be transferred to NSD's Regional Database

Eurostat Workshop, Luxembourg, 3 and 4 December 2008



## Data from Registers – Possible Future Solution

### Why are both Statistics Norway and NSD focusing on services based on extended cooperation in this area?

- Register data constitute a gold mine for many scientific fields; economy, sociology, medicine, demography, heavily underused
- For SN data provision through NSD (as safe data service) is seen as an important tool - complimentary to other access mechanisms and services already provided and to be established in the future
- Based on a recognition that various access mechanisms meet various demands and thus supplement each other
- Solve (to a great extent) problems involving costs of factual anonymisation and services
- A rich data resource that potentially gives Norwegian researchers a clear advantage compared to other (non-Nordic researchers)
- There is a clear potential for close Nordic cooperation within this area



## The lesson learned - the Norwegian Model

- Cooperation and partnership work
- Laws and regulation do not necessarily lead to restricted or no access
- An adequate legal framework is important to safeguard privacy as well as access to rich data

## **Future Models for Data Access – The Role of CESSDA RI**

ESFRI PPP - Develop CESSDA into robust European wide institutional framework on sound financial and legal footing.

Constitute a potential efficient and cost-effective data provision tool for data producers (national statistical agencies and other governmental bodies), ensuring wide access to a variety of data sources for research purposes and at same time protecting the privacy interests in relation to the data