SHARING RESEARCH DATA IN THE NORDIC COUNTRIES:

New data protection rules in the EU open doors to Nordic research

Norway, Sweden, Denmark and Finland: three EU countries and a single EEA nation. The EU’s new personal data protection regulations will apply to everyone. On May 25, 2018, a comprehensive set of laws will provide new guidelines for how personal data may and may not be utilised, for example in research. Until that date, each country can interpret, adapt and shape the new legislation.

A Norwegian initiative, led by NSD, aims to contribute to improved Nordic coordination of laws and regulations for personal data protection in research. Norway is chair of the Nordic Council in 2017.

“This provides the Nordic countries with an opportunity to coordinate both regulations and practices. Nordic coordination should make it easier to share data, including register data, among themselves. At the same time, we can ensure that we avoid a dilution of the conditions under which researchers are placed. All in all, this should stimulate more cross-border research. All in all, this should stimulate more cross-border research. From the perspective of the researchers, this is in many ways a positive reform that we have been handed by the EU. The regulation primarily maintains and also partially reinforces important exceptions that make it possible to use personal data for research purposes,” says NSD Associate Director Vigdis Kvalheim.

The Nordic model
Implementing something is not merely a matter of defending it. It also offers an opportunity to reinforce it.

“If the Nordic nations join forces on this task, it will make everyone stronger. These countries already cooperate over a wide range of tasks, and have a great deal in common. As far as register data are concerned, the Nordic countries have unique resources in an international context. This makes it natural for us to draw up a common framework for how the regulations should be interpreted and practised in research. This could be of great importance, for example for medical research,” says Kvalheim.

NSD is leading this project, which also includes SND (the Swedish National Data Service), DDA (the Danish Data Archive) and FSD (the Finnish Social Sciences Data Archive). Starting off with a joint working group, the aim is to map out the consequences of the EU’s regulations and, above all, to see what new opportunities open up.

The most important task for the working group will be to analyse where the regulations differ, or are practised in ways that prevent data from being shared across national borders. The aim is to map out the consequences of the EU’s regulations and, above all, to see what new opportunities open up.

Without borders
By the end of 2017, core participants will be drawn into this task. Researchers, data producers, ethics committees and others will provide input regarding where something needs to be done.

“We will examine the possibilities, and in this way, strengthen the Nordic research community,” says Kvalheim.
The joint effort will generate advice to the Nordic Council of Ministers, and the national authorities regarding how a common set of regulations can best be arrived at. The EU regulations aim at a continuation of the researcher-friendly laws for the use of personal information that already exist in the Nordic region. However, different interpretations and practices in each individual country could put a spoke in the wheel for more, and simpler, sharing of data, which is an aim of research policy in both the EU and the Nordic countries.

“Our goal must be a border-free Nordic region for research. If we manage to harmonise, researchers in the Nordic countries will gain much in the form of access to data across national borders,” says Kvalheim.

**NEW PERSONAL DATA PROTECTION REGULATION**

New forms of data do not recognise national borders. More international cooperation and harmonisation of legislation and ethical principles are needed, according to an OECD report. Research that involves new types of data is leading to new ethical challenges. The concept of “new forms of data” encompasses data that are collected for purposes other than research, including administrative and register data. It also includes data gathered from the digital tracks left every day by Internet users, for example when they read the news or buy milk. Such data are often put to commercial use, but they can also be useful for research. Just how legal, political, economic and ethical aspects should be dealt with in this connection is not at all clear, precisely because these types of data are new. The OECD report takes up this problem, and wants us to start with the ethics.

Technology is steadily developing, and current laws and regulations are inadequate.

**Every day people leave digital traces behind using the Internet**

![Digital Traces](image)

**MY NSD**

**Line Synnøve Bystrøm**, financial economist. Used data supplied by NSD/Living Conditions Survey (Statistics Norway) in her MSc dissertation at NTNU.

I have used data from NSD in my MSc dissertation in financial economics, which I wrote together with my fellow student Synne Almaas. The thesis deals with households that refinance their mortgage in order to use the money freed up for consumption. Our point of departure was findings from the USA before the emergence of the crisis. It turned out that people who refinanced their mortgages were those who suffered most when the crisis arrived. Norway has an extremely high rate of growth of debt, over 200 per cent of disposable income. We wanted to find out if the same effect applied in this country, and we confirmed that it did. Mortgage refinancing is a significant contributor to our high load of debt. In an article based on the dissertation that we subsequently wrote, we showed that people who take out money in this way, are those who most often experience problems in repaying their debt. We were tipped off about NSD by Statistics Norway. Finding our way around the data-sets was very straightforward, and I was impressed by NSD’s short response time!
New forms of data are so complex that basic philosophical and ethical principles need to be taken up and reassessed. In turn, ethical principles will have to be related to legal frameworks, and to legislation capable of regulating how data are used. The report points out that legislation in itself is not sufficient. While laws lay down what we may not do, ethics deals rather with what we ought not to do.

There are wide variations between regulations in different countries today. Norway is one country which has comprehensive legislation and an ethical framework in place, largely in accord with the recommendations of the OECD report. The report recommends that data archives, financing institutions and researchers should share their knowledge and experience, what it calls “best practice”, in order to establish and maintain a secure framework for the sharing of data.


EU General Data Protection Regulation

- In 2016, the EU adopted a regulation that in May 2018 will replace its Personal Data Protective Directive of 1995.
- The regulation aims to harmonise EU and EEA legislation and adapt it to the digital age. At the same time, the rights of the individual regarding the use of personal data will be strengthened.

EDUCATION NEWS

Every fifth position in higher education is temporary. 2016 was a record year for student exchanges. Bioengineering students are drawn to Ålesund. These are just a few of the items you can find in the most recent (2016) statistical survey of higher education in Norway, which has just been published by NSD. The Database of Higher Education Statistics (DBH), which is run by NSD, provides data regarding students, doctorates, publishing, economics, internationalisation, libraries and university museums. The data can be accessed by everybody, and are most frequently used by the authorities, the press and the research sector. nsd.no/dbh

CRONOS: A MULTINATIONAL WEB PANEL

NSD plays a central role in the ground-breaking project CRONOS (CROss-National Online Survey), which aims to test the potential for developing a multinational web panel based on probability samples. The data collection and the administration of the surveys in the participating countries will be administered from a central system run by NSD. The respondents will be recruited in connection with the personal interviews conducted by the ESS (European Social Survey). The recruitment to the web panel and the following data collection processes will take place in three countries: Estonia, Slovenia and the United Kingdom. NSD will run the panel database, set up the web questionnaires and be responsible for distributing, invitations and for six surveys in the course of a year. NSD is also the data archive for the project. CRONOS is part of the project “Synergies for Europe’s Research Infrastructures in the Social Sciences (SERISS)”, which is financed by the EU’s Horizon 2020 Programme.

NORDi: NEW SERVICE FOR DEPOSITING DATA

NSD’s new service will make it easier to deposit and deliver data for all types of research projects. The new service has a simple drag-and-drop function to which relevant data files and documentation files can be uploaded. Users can log into the system via Feide, (Norwegian acronym for the Common Electronic Identity System), which is the Ministry of Education and Research’s chosen system for secure identification in the educational sector. The service is being developed in NSD NORDi, which will make it easier to find, use and share data.
Researchers are traditionally used to thinking in terms of “publish or perish”. Publications are a means of profiling your worth as a researcher, as a candidate for a tenured position or a potential recipient of project funding. But behind every successful publication lie research data that traditionally are NOT the object of equivalent recognition in the incentive systems of researchers. However, rapid technological development has made it possible to change how research is done and how results are shared, and on the political level, pressure to share research data is growing. For example, the EU Horizon 2020 Programme requires data to be made available in quality-assured archives that are “as open as possible, as restricted as necessary”, from 2017 onwards.

If data are to be shared, they must be well structured, documented and securely archived, retrievable and comprehensible to as many people as possible. They must also be available as openly as possible within the limitations imposed by the regulations.

Why should researchers devote time to this, when they are already drowning in requirements to write grant applications, papers for conferences, evaluate other researchers’ papers and supervise students? Especially when all they really want to do is more research?

For researchers, there are five main reasons for doing this:

Visibility: At NSD, archived data sets are given a homepage ("landing page") and a DOI (Digital Object Identifier) which makes research data easy to cite. The DOI is accompanied by key information about the data, thus profiling the researcher, the project and the data themselves. The traceable DOI also simplifies the process of showing how often the data set has been shared, cited and used.

Documentation: How many researchers can still remember the detailed documentation from a project that came to an end five years ago? Good structure and documentation not only ensure that others can read and use data in five years; they also help the original producer of the data to use them herself. NSD has wide experience of data documentation and can help researchers to preserve relevant information.

Security: Archiving material in a certified archive gives researchers security. Their data are securely stored, even if a laptop crashes or the USB memory stick disappears.

Integrity and trust: Making source data visible gives the researcher integrity, because it allows results to be checked by others. Quality-assured archiving also guarantees that data are not manipulated. This in turn leads to more transparent research and greater confidence in the research process.

Networks: Sharing data opens new doors. In 2015, there was a great deal of interest in the fact that a linguist and a social scientist published in a Nature journal. Two factors led to this success: a new method and new data. These researchers obtained their data via the Citizen Panel (“Medborgerpanelet”, which is archived at NSD), where they submitted an open question: “What do you think when you hear or read the phrase ‘climate change’?” In order to structure the more than 2000 self-formulated responses, the researchers utilised topic-modelling methods from linguistics research. The cross-disciplinary combination of methods, professional insight and data, offered the researchers completely new insight into how people think about climate, insight that no-one had previously obtained.

However, researchers cannot expect to share their data at the end of a research project without being trained in how to do so. Researchers need systematic training in order to develop a culture oriented towards, and competence in, sharing. Via the NORDi project, NSD is working to remove barriers against sharing research data. It ought not to take much time to share or find research data. Nor should it be complicated. And sharing data should be both natural and necessary, not merely because research policies require it, but because it also serves the researchers themselves, both today and in the future.

Cold facts

TNS Gallup AS, 1973:
President Nixon has visited China and The Soviet Union. Do you believe these visits have contributed to reducing the risk of war in the world?  
No 34 %  Yes 66 %

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