



Vetenskapsrådet

# INTERNATIONAL EVALUATION OF THE SWEDISH NATIONAL DATA SERVICE, SND

# **INTERNATIONAL EVALUATION OF THE SWEDISH NATIONAL DATA SERVICE, SND**

October 16-18, 2011

INTERNATIONAL EVALUATION OF THE SWEDISH NATIONAL DATA SERVICE, SND

SWEDISH RESEARCH COUNCIL  
VETENSKAPSRÅDET  
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# PREFACE

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The Swedish Research Council is a governmental agency with the responsibility to support basic research of the highest scientific quality in all academic disciplines. It is also part of the Council's remit to evaluate research and assess its academic quality and success.

The Council for Research Infrastructure at the Swedish Research Council has the overall responsibility to ensure that Swedish scientists have access to research infrastructure of the highest quality. Specifically, the Council evaluates the needs for research infrastructure in a regularly updated road-map, launches calls and evaluates applications, participates in international collaborations and works on monitoring and assessments.

In 2008 the Swedish Research Council initiated a new organization, SND (Svensk Nationell Datatjänst) as a sequel to SSD (Svensk samhällsvetenskaplig datatjänst) established in 1981. SSD was an initiative from Humanistisk-Samhällsvetenskapliga forskningsrådet with the focus of archiving and disseminating data within the social sciences. In the transition from SSD to SND the scope was enlarged to cover social and medical sciences as well as the humanities. A call for a host organization for SND was launched, that Gothenburg University won.

In October 2011 an international expert panel convened in Gothenburg to review the Swedish National Data Service (SND). The panel was requested to examine SND as a national resource and to give advice on the future development of this resource. In doing so, the panel should consider the role of SND as one of the actors in the broad data infrastructure landscape. The panel should focus on how well SND as a provider of services to the Swedish research community fulfils its mission focusing on:

- The scope of SND's mission
- SND's role in international collaboration
- SND as a facilitator for access to data
- SND's organization and personnel

This evaluation report constitutes an independent statement from the international expert panel. The recommendations will serve as a basis for further discussion on the future direction of SND.

The Swedish Research Council would like to express its sincere gratitude to the members of the expert panel for devoting their time and expertise to this important task.

The Swedish Research Council would also like to thank SND and the representatives of SND user groups for providing background material and for giving informative presentations.

Stockholm 2012-11-20

Juni Palmgren  
*Secretary General*  
*Council for Research Infrastructures*  
*Swedish Research Council*

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# SVENSK SAMMANFATTNING

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År 2008 initierade Vetenskapsrådet omvandlingen av SSD (Svensk Samhällsvetenskaplig Datatjänst) till SND (Svensk Nationell Datatjänst). Enligt överenskommelsen mellan Vetenskapsrådet och Göteborgs universitet (värduniversitet för SND) ska SND fungera som en service- och stödfunktion för svensk forskning inom humaniora, samhällsvetenskap och medicin. Som sådan ska man erbjuda bl.a. tekniska och juridiska resurser för att samla in, lagra och distribuera data för forskning inom dessa områden. Under två dagar i oktober 2011 sammanträdde en internationell panel i syfte att utvärdera SND. Utvärderingen tillkom på initiativ av Vetenskapsrådet och Göteborgs universitet vilka har ett delat ansvar för SND. Panelen hade ombetts att undersöka SND som en nationell resurs men även att föreslå möjliga utvecklingar av denna resurs. Panelen skulle i sitt arbete fokusera på fyra faktorer: 1) Kärnan i SND:s uppdrag; 2) SND:s roll i ett internationellt samarbete; 3) SND:s underlättande av tillgång till data samt 4) SND:s organisation och personal. Panelen kom fram till att:

- Det finns ett behov av en nationell dataservice för forskning som en del av Sveriges forskningsinfrastruktur.
- SND är i en bra position för att fylla detta behov.
- Vetenskapsrådet bör satsa långsiktigt på SND.
- SND i sitt arbete bör prioritera att 1) nå ut med sin service till forskarsamhället, 2) inventera forskningsdata, 3) utveckla expertkunskap i hur man skyddar personuppgifter och den enskildas integritet, samt 4) skapa möjligheter att handha konfidentiell forskningsdata.

Panelen noterade att det finns såväl strukturella som organisatoriska hinder för registerbaserad forskning i Sverige vilka adresseras i slutet av denna rapport.

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## EXECUTIVE SUMMARY

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- The panel stresses the need for a national data service for research as an essential part of Sweden's research infrastructure.
- The panel encourages the Swedish Research Council, SRC, to make a long term commitment to this service.
- The panel concludes that the Swedish National Data Service, SND, is in a good position to fill this role. This report contains suggestions for further development of SND.
- The panel recommends the following priorities for SND development: Outreach to research communities, inventory of research data, development of expertise in human subjects protection, and creation of facilities for managing confidential data.
- The panel noted structural and organizational obstacles for register based research in Sweden, and has taken the liberty to address these points at the end of this report.

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# INTRODUCTION

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On 16-18 October 2011 an international panel convened in Gothenburg to review the Swedish National Data Service (SND). The review was requested by the Swedish Research Council (SRC), which shares the responsibility for the SND with the Gothenburg University. In the original call for a host university for SND, it was stated that follow ups and evaluations would be the responsibility of the Council for Research Infrastructures at SRC and to be conducted with the help of international expertise <sup>1</sup>.

The panel was requested to examine SND as a national resource and to give advice on the future development of this resource. In doing so, the panel should consider the role of SND as one of the actors in the broad data infrastructure landscape. The panel should focus on how well SND as a provider of services to the Swedish research community fulfils its mission focusing on:

- The scope of SND's mission
- SND's role in international collaboration
- SND as a facilitator for access to data
- SND's organization and personnel

The panel was provided with four background documents prepared by SND on each of the four points listed above. Juni Palmgren informed the panel about the historical background, and the initiative taken by SRC in 2008 to transform the previous Swedish Social Science Data Service (SSD) into an SND with a broader mandate. Juni Palmgren stressed that the panel should look forward and provide advice for the future. The panel met and had extensive discussions with Pam Fredman (Vice-Chancellor of the Gothenburg University); Hans Jørgen Marker (Director of SND); and Rune Åberg (Chairman of the board of SND). Experiences from SND users were presented by Michael Gähler (Level of Living Survey, Stockholm University); Eva Bernhardt (Young-adult panel survey, Stockholm University); and Urban Lindgren (SIMSAM Microdata research on childhood for lifelong health and welfare, Umeå University). Eva Stensköld served as secretary for the panel.

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<sup>1</sup> Call for a host university, Dnr: 811-2006-7414



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# BACKGROUND OF SND

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SSD (Svensk samhällsvetenskaplig datatjänst) was established in 1981 as an initiative from Humanistisk-Samhällsvetenskapliga forskningsrådet. It started out as a project with the aim of archiving and disseminating data within the social sciences, and in 1985 it was established as a unit under the faculty of social science at Gothenburg University.

In 2008 the Swedish Research Council initiated the transformation of the old SSD into a new organization, SND (Svensk Nationell Datatjänst). A call for a host organization was launched, that Gothenburg University won.

A director for SND was recruited in 2008, but unfortunately the director left the assignment by the end of the same year, forcing SND to restart the recruitment process. Björn Halleröd (Professor of Sociology at Gothenburg University) served as an interim director for the period January-September 2009. In September 2009 Hans Jørgen Marker was recruited as the director of SND.

Simultaneously, the Swedish Research Council launched other initiatives in order to support the development of Swedish register based research; the SIMSAM initiative (Swedish Initiative for Research on Microdata in the Social and Medical Sciences)<sup>2</sup>, the MONA-system (Microdata-ON-line-Access)<sup>3</sup> and DISC (Database Infrastructure Committee)<sup>4</sup>.

The agreement between the Swedish Research Council and Gothenburg University states that SND should function as a service organization for Swedish research within the humanities, social sciences and health sciences.

The original call for tender from the Swedish Research Council described SND's assignment to include:

- Archiving, quality assurance, and documentation of existing research databases.
- Efforts to keep these databases readily accessible for research.
- A coordinating function for data that is archived in separate institutions, for example government authorities and international data archives.
- Research services with advice and information on existing data and other support to researchers in terms of data access, organization and use of large amounts of data.
- Active cooperation and participation in international networks for data archives, and cooperation with various parties on issues relating to the development and building of databases.

It was also stated that SND, within five to ten years, should have complete knowledge concerning Swedish research, particularly within social medicine, social sciences and humanities as well as an overview of the research in other countries.

In the contract between the University of Gothenburg and the Swedish Research Council, the mission was described as follows:

"Within the framework of this agreement, the University of Gothenburg shall via SND meet the research community's need for data for empirical research in the areas of social science, humanities and medicine. The commitment includes the provision of resources within data technology, legislation, knowledge and administration for the collection, storage and distribution of data for research."

*The panel acknowledges that SND has had serious difficulties in recruiting a director, thus delaying the functional organization for approximately a year. These difficulties were beyond the control of SND.*

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<sup>2</sup> The Swedish Research Council granted six research projects and one graduate school to a total of somewhat more than 135 million SEK for five years

<sup>3</sup> The MONA-system was launched by Statistics Sweden in 2005, it is co-funded by the Swedish Research Council

<sup>4</sup> Today DISC functions as an expert group to the Council for Research Infrastructures at the Swedish Research Council

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# THE ROLE OF SND IN THE SWEDISH RESEARCH COMMUNITY

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The panel believes that SND's role in the research community is best characterized by its competencies (areas in which SND has skills and expertise) and capabilities (activities and services offered by SND). The following lists begin with competencies and capabilities that SND has already achieved and continue with areas recommended by the panel for development in the near future.

The panel commends the SND for developing a core staff with the skills to provide the essential functions of a data archive. We have confidence that SND has established competencies in relevant (i) research process, (ii) data management, and (iii) data and metadata. SND is also a fully functional data archive providing capabilities (1) through (5) below. Our discussions with the SND Chair, Director, and users have convinced us that the additional capabilities described below are within reach and would be important additions to the research infrastructure for all of Sweden.

The panel recognizes that the relationship between SND and the humanities remains to be defined, and requires more consideration and investigation than was possible in this review. SND started out working with social sciences and health registers, and has further developed this expertise. For the humanities SND and its users still need to define SND's role. In the following, the panel analysis and recommendations focus on the two fields of social sciences and health registers; this should not be seen as a negative evaluation, but simply as a note that the panel was unable to evaluate this part of the activities.

## Competencies

- i Understanding of the research process in each of SND's initial core communities: social sciences and health
- ii Management of research data across the data life cycle from initiation of research to dissemination for secondary analysis by other researchers
- iii Documentation and preparation of research data according to international standards for data and metadata
- iv Digital preservation
- v Analysis of disclosure risks in quantitative data for the protection of human subjects
- vi Data security
- vii Ethical conduct of research and legal protections for human subjects under Swedish law
- viii Understanding of the research process in humanities

## Capabilities

- 1) Archive and document research data from social sciences, health, and humanities
- 2) Provide secure long-term preservation of digital resources
- 3) Produce accurate and complete documentation of data
- 4) Offer a comprehensive online catalog of data resources in Sweden
- 5) Disseminate data to the research community
- 6) Archive and document research data and tools from humanities
- 7) Reach out to the academic community to communicate SND competences and capabilities
- 8) Support users of research data
- 9) Provide training in data management and research methods
- 10) Advise researchers and other digital archives on the management of research data across the data life cycle
- 11) Advise researchers on the ethical and legal aspects of research data about human subjects
- 12) Analyse data collections for risks that confidential information may be compromised by re-identification of subjects and recommend procedures for sharing data consistent with those risks

- 13) Safely manage and distribute data sets when the risk of re-identification of subjects cannot be fully eliminated
- 14) Administer a secure facility in which data with personal identifiers can be safely stored, merged with other sources, and provided to researchers in either anonymized form or under appropriate security conditions

The Panel also received valuable information about research based upon Sweden's extensive system of administrative registers. We believe that these rich resources offer exciting opportunities for research on interactions between social conditions and health and other important topics, but researchers seem to be frustrated from realizing this potential by the complex legal and administrative situation in Sweden. Resolving this situation will require coordinated action at a high level as we recommend in section "Swedish register based research".

### Priorities for developing SND into a full archive and knowledge center:

**Outreach and communication.** *The panel recommends that SND develop a clear and concise message describing the importance of its services and the benefits it provides to the research community.* The panel was encouraged that SND is establishing contacts with researchers, libraries, and archives throughout Sweden, but it is evident that the capabilities of SND are not well known. Potential partners, such as universities, should see SND as a resource that can help them deal with the challenges of archiving research data and tools, which is usually unfamiliar to them.

**Inventory of research data.** *The panel recommends that high priority should be given to establishing a comprehensive inventory of Swedish research data.* This inventory can be used as a basis for a national discussion on developing an open access policy for Swedish research data.

**Protection of human subjects.** *The panel strongly recommends that the SND develop expertise in the ethical and legal protections of human subjects for research in Sweden.* Developments in research methodology and new technologies, such as data mining, have increased the risks that subjects can be re-identified even when direct identifiers (such as name, address, and person number) have been removed. The science and practice of evaluating disclosure risks in research data is a large and growing field. SND can become an important resource for researchers by becoming a center of knowledge about the ethical, legal, and scientific aspects of protecting subjects in data used in social and health research. SND should provide advice to researchers that will help them navigate the complexities of the current regulatory environment.

**Managing confidential data.** *The panel recommends that SND develop services for managing confidential data.* This should include analysis of disclosure risks in data sets, procedures for anonymizing data, and facilities for sharing data that cannot be fully de-identified. In the short run, SND should offer these services to researchers in academic and research institutions. In the medium term, SND should be part of the solution for providing access to data derived from Sweden's extensive register systems. The panel believes that the best way for SND to prepare for this role is to establish expertise, experience, and reputation as a reliable provider of secure access to confidential data.

## Tasks for the medium term

To continue to develop the core activities of SND and to address the priorities listed above, the panel makes the following recommendations for the work of SND in the next 3-5 years:

Continue and expand work in acquiring, archiving, documenting, curating, and disseminating data (capabilities 1-5):

- Define the scope of the research data that should be archived by SND in each of its disciplinary areas.
- Identify and locate all the relevant data in Sweden.
- Produce a comprehensive catalogue of these data.

- Participate in international standards organizations, like the DDI Alliance.
- Produce documentation and other metadata of the data in standardised forms, in Swedish and English.
- Make the data and metadata available through the SND website, including links to other depositories where appropriate.
- Identify relevant international data sources, and provide links to them from the SND website.

Continue and increase work on outreach and communication:

- Establish a network of contacts in all Swedish universities.
- Publicise the services of SND through regular visits to universities, academic conferences and other forums.
- Provide information on SND for universities to use in their training of research students, such as the SIMSAM graduate school.
- Develop a training program in data management and research methods.

Continue to develop the SND's role as a knowledge centre and source of advice:

- Acquire in-house expertise in human subjects protection and managing confidential data.
- Collect information on best practice internationally.
- Produce user's guides in topics such as data management, human subjects protection, data security.
- Develop procedures for different levels of access to confidential data.

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## INTERNATIONAL COOPERATION

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It is important for a national research infrastructure to participate in and contribute to international activities in their field and SND has a good track record. International cooperation is beneficial for Sweden because it brings experiences and insights.

The director of SND is currently president of Council of European Social Science Data Archives (CESSDA) and had been member of CESSDA executive board since 1999. *The panel recommends that Sweden join the CESSDA ERIC.*

SND has been able to attract some EU contracts, and lately has attracted the DASISH project which SND is coordinating. In DASISH all five ESFRI research infrastructures in the Social Sciences and Humanities collaborate.

Apart from CESSDA and other EU contracts, the SND also participates in relevant international associations and activities such as IFDO, ICPSR and DDI Alliance.

*The panel considers SND's participation in international activities appropriate and commends the coordination of DASISH as an accomplishment.*

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# GOVERNANCE AND ORGANIZATION OF SND

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SND needs a well defined organization and leadership. The panel offers the following recommendations.

## Statutes

According to the documentation that the panel has received, SND has a well defined set of aims for the data archive. Needed also are statutes for the organization and leadership of SND. Such a document is important in defining the relationships between the SRC, Gothenburg University, the board and the director of SND.

*The panel recommends that statutes for SND be formulated and decided by Gothenburg University and the SRC.*

## Board

Currently, the board of SND is decided through a nomination process between Gothenburg University, the SRC and the advisory board of SND. The panel believes that the board of SND should be nominated and decided in dialogue only between the SRC and Gothenburg University. Since SND is a national infrastructure, the SRC should assure that the board has a national expertise and is composed of people with real interest in the development SND. The board's expertise should also reflect the main areas of operation of SND. The board should be encouraged to invite international expertise (for example directors from organizations like SND) as observers to their board meetings.

*The panel recommends that the board and chair be decided in dialogue between Gothenburg University and the SRC and that the national interest and expertise be reflected in its composition.*

## Delegation of responsibilities

Delegation between the board and the director needs to be clear. A delegation specifying areas of responsibility must be formulated. The panel believes that the main role of the board is to discuss and approve short- and long-term strategies, finance, annual reports, and annual work plans. Operational decisions should be delegated to the director in accordance with the principles of delegation at Gothenburg University.

*The panel recommends that a delegation for SND should be formulated.*

## User groups

The panel believes that there should be closer communication with the end users of SND. This could be achieved by setting up user groups, reflecting the main responsibilities of SND –social sciences, health sciences and humanities. These user groups, which could be kept relatively small, would act as support groups for the research coordinators of SND.

*The panel recommends that user groups should be set up in social sciences, health sciences and humanities.*

## The scientific advisory board

The current role and function of the scientific advisory board is not entirely clear. The panel believes that the national interest and necessary expertise should instead be reflected in the board and by inviting international expertise as observers to their meetings.

*The panel recommends that the advisory board should be dissolved and that its area of expertise will instead be reflected in the composition of the board, by inviting experts as observers to board meetings, and by setting up user groups.*

### **Host organization**

The panel noted the good collaboration between SND and Gothenburg University and was impressed with the way in which the university is committed to the responsibility of housing SND.

*The panel encourages the commitment of Gothenburg University to its role as steward of SND and to building Sweden's national research infrastructure.*

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# WAYS THAT THE SWEDISH RESEARCH COUNCIL CAN HELP THE SND ACCOMPLISH ITS MISSION

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1. Require all research proposals to include data management plans specifying procedures for managing, documenting, preserving, and sharing data created during the project. Data management plans were recently required by the U.S. National Science Foundation and promoted by the Joint Information Systems Committee in the U.K.
2. Assure that valuable research data is shared. Publicly financed data collections should be publicly available. Researchers need support and encouragement to prepare their data for analysis by other scholars. Open Access policies need to be developed and implemented at the Swedish Research Council.
3. Encourage all Swedish Journals and other publications to cite data consistently in the same way that publications are cited. Data citations encourage data sharing by recognizing the contributions of data producers. Data citations should also include persistent identifiers, such as digital object identifiers (DOIs), which assure long-term access to data resources. As a member of Data Cite, SND should be the distributor of DOIs for data in Sweden.
4. Coordinate efforts to change legal and regulatory structures to facilitate sharing of data and to simplify access to administrative data.



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# A VISION OF THE SND OF TOMORROW

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- The SND website is the first place that researchers go to find data. The SND catalogue is a comprehensive source for discovering social science, health and humanities data in Sweden.
- Researchers turn to the SND to develop a data management plan at the beginning of a research project.
- All data produced by social science, health and humanities researchers is offered to SND for archiving, preservation and dissemination. Libraries and digital archives ask SND for advice and assistance when they archive social science, health and humanities data.
- SND is a recognized authority on protection of human subjects. Data producers turn to the SND to evaluate disclosure risks in their data and to devise measures for safely sharing their data.
- SND provides facilities for creating and sharing complex data derived from population and health registration systems. SND creates de-identified public-use versions of these data for wide distribution and facilitates secure access to data that must be protected.

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# SWEDISH REGISTER BASED RESEARCH

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Sweden has a long and well established tradition of civil registration and Sweden was the first country to introduce personal identification numbers. This was clearly recognized in the 2008 Bill for Research and Innovation<sup>5</sup>. Sweden is therefore in a very strong position to be an international leader in research, based on linkage of data from administrative, social and health registers. The widespread use of the multigenerational register in cancer research in Sweden is a good example of this.

The panel has, however, noted legal and organizational obstacles to the further development of register-based research in Sweden<sup>6 7 8</sup>. In 2008, SRC granted money for new register-based research initiatives under the SIMSAM programme. The panel was informed that it has been extremely cumbersome to realize some of these SIMSAM initiatives. It appears that the ethical committees lack a framework for permitting the construction of databases for general research questions. The National Board of Health and Welfare does not have a tradition or a procedure for transferring data for linkage within Statistics Sweden, and Statistics Sweden has been very reluctant to release data containing personal information to external users in the current legal environment. As a consequence, three years of research time have now been spent on trying to overcome these obstacles. The panel is aware that these issues remain unsolved despite previous initiatives from the SRC.

Despite the great potential for register-based research, Sweden is at an immediate risk of not staying in the forefront of this research area. In the present situation, register-based research in Sweden is too slow and too expensive to be internationally competitive.

*The panel therefore recommends that Sweden form a high level committee including the political responsible partners for SRC, Statistics Sweden, the National Board of Health and Welfare and other key stakeholders to remove the legal and organizational obstacles for the further development of register-based research in Sweden.*

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<sup>5</sup> Prop.2008/09:50

<sup>6</sup> Rättsliga förutsättningar för en databasinfrastruktur för forskning, Vetenskapsrådets rapportserie 11:2010

<sup>7</sup> Översyn av de nationella kvalitetsregistren. Guldgruvan i hälso- och sjukvården. Förslag till gemensam satsning 2011-2015

<sup>8</sup> Kommittédirektiv (Dir 2011:32) Översyn av Statistiska centralbyrån och statistiksystemet

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# APPENDIX 1

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## Participating in the evaluation

### Chair of panel

Anders Brändström (*chairman*), *Historical demography, Umeå University (SWE)*

### International panel

George Alter, *Population Studies Center, University of Michigan (USA)*

Jouni Kuha, *The Methodology Institute, London School of Economics (UK)*

Elsebeth Lyngø, *Department of Public Health, University of Copenhagen (DK)*

Bente Maegaard, *Centre for Language Technology, University of Copenhagen (DK)*

### Participating from Gothenburg University

Pam Fredman, *Vice-Chancellor of the University of Gothenburg*

### Participating from SND

Hans Jørgen Marker, *Director of SND*

### Participating from the SND board

Rune Åberg, *chairman of the board of SND*

### Participating from the Swedish Research Council

Juni Palmgren, *Secretary General Research Infrastructures*

Eva Stensköld, *Research Officer Research Infrastructures, panel secretary*

### User groups

The Swedish Level-of-Living survey (LNU) Michael Gähler, *SU/SOFI*

<http://www.sofi.su.se/pub/jsp/polopoly.jsp?d=9324>

Young Adult Panel Study (YAPS) Eva Bernhardt, *SU/SUDA*

<http://www.suda.su.se/yaps/>

The Umeå SIMSAM node, Urban Lindgren

<http://www.phmed.umu.se/english/divisions/epidemiology/research/the-umea-simsam-node/>

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## APPENDIX 2

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### International Evaluation of Swedish National Data Service (SND), 16–18 October 2011, evaluation scheme

The evaluation will be held in the premises of SND, in Gothenburg, Sweden – se link for address, contact information and map:

<http://snd.gu.se/en/about-us/contact-us>

#### Schedule

	<i>Sunday, 16 October</i>	<i>Monday, 17 October</i>	<i>Tuesday, 18 October</i>	
8.30–9.00	Arrival	Panel closed session	Report drafting	
9.00–10.00		Session 1		
10.00–11.00				
11.00–12.00		Lunch		
12.00–13.00				
13.00–14.00		Session 2		Report drafting
14.00–14.45		Coffee break		
14.45–15.00				
15.00–16.00		Session 2		Report drafting/ summing up
16.00–17.00		Session 3		
17.00–18.00				
18.00–19.00	Introductory meeting	Departure		
19.00–	Dinner			

#### SUNDAY 16th of October

##### Introductory meeting

18:00–18:15 Welcome Juni Palmgren

18.15–18.30 Tour de table

18:30–18.45 International Evaluation of SND Juni Palmgren

18.45 Departure for dinner

19:00– Dinner

##### Participating in dinner:

- Panel members
- Chairman (will join us at the restaurant)
- Juni Palmgren
- Eva Stensköld

## MONDAY 17th of October

### Session 1 – Presentation of SND and its mission

09.00–09.15 Introduction (chairman) panel +SRC<sup>9</sup> only

09.20–09.45 Presentation by Pam Fredman (Vice-Chancellor of the University of Gothenburg)

09.45–10.00 Questions

10.05–10.30 Presentation by Hans Jørgen Marker (Director of SND)

10.30–10.45 Questions

10.45–11.00 Short break

11.00–11.25 Presentation by Rune Åberg (Chairman of the board of SND)

11.25–11.40 Questions

11.00–12.00 Summing up/discussions (chairman+panel) panel+SRC only

### Session 2 – SND user groups

13.00–13.15 Introduction (chairman) panel+SRC only

13.20–13.35 user group 1 – Michael Gähler<sup>10</sup>

13.35–13.45 Questions

13.50–14.05 user group 2 – Eva Bernhardt

14.05–14.15 Questions

14.20–14.35 user group 3 – Urban Lindgren

14.35–14.45 Questions

14.45–15.00 Coffee break

15.00–17.00 Summing up/discussions (chairman+panel) panel+SRC only

### Session 3 – Future needs and outlook

17.00–17.15 Introduction Juni Palmgren

17.15–18.45 Discussion (chairman+panel)

18.45 Departure for dinner

19.00– Dinner

Participating in dinner:

- Panel members
- Chairman
- Juni Palmgren
- Eva Stensköld
- Hans Jørgen Marker (Director SND)

## TUESDAY 18th of October

8.30–12.00 Report drafting

12.00–13.00 Lunch

13.00–14.45 Report drafting

14.45–15.00 Coffee break

15.00–17.00 Report drafting/summing up

17.00–18.00 Draft report presentation for Swedish Research Council<sup>11</sup>

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<sup>9</sup> Swedish Research Council

<sup>10</sup> Participating through telephone

<sup>11</sup> I know that some of the panel members have flights leaving 18.40, therefore the draft report presentation might have to be scheduled somewhat earlier than in the schedule.

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# APPENDIX 3

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## Terms-of-reference for international review of SND (Swedish National Data Service) 2011

### Introduction

SND (Swedish National Data Service) is a service and support organization for data on empirical research in the areas of social science, humanities, and medicine. SND should provide technical, legal, educational, and other administrative resources for collecting, storing, and distributing data for research within these fields.

SND's assignment includes:

- Archiving, quality assurance, and documentation of existing research databases.
- Efforts to keep these databases readily accessible for research.
- A coordinating function for data that is archived in separate institutions, for example government authorities and international data archives.
- Research services with advice and information on existing data and other support to researchers in terms of data access, organization and use of large amounts of data.
- Active cooperation and participation in international networks for data archives, and cooperation with various parties on issues relating to the development and building of databases.

An international review of SND will be conducted during 2011. The role of the review is to examine SND as a national resource and to give expert advice on the future development of this resource.

In doing so the panel should consider the role of SND as one of the actors in the broad data infrastructure landscape for the disciplines concerned, a description of which will be supplied to the panel.

Additional material for the assessment will be supplied by SND and by users/user communities. On-site meetings will be arranged during the panel meeting in Stockholm with people representing various functions of SND and with users/user communities. After completion, the results and conclusions of the review will be made public in a written report.

### Review Panel

The review will be conducted by a panel consisting of internationally recognized experts with broad expertise in the various activities that fall under the responsibility of SND. None of the members shall be personally engaged in the activities at SND.

The chairperson of the Review Panel will be appointed by the Swedish Research Council and the Council for Research Infrastructures (RFI). The Chair leads the review and is the rapporteur of the Panel. A research officer from the Swedish Research Council acts as the co coordinator of the review.

### Review Schedule

The review shall be made during **October 16-18, 2011**, in Stockholm, Sweden. A preliminary report, including the main findings, shall be presented to the Swedish Research Council by the rapporteur or his/her representative, on **December 8, 2011**. Material on which the review shall be based will be distributed to panel members no later than **September 1, 2011**.

### Review Procedure

The assessment should focus on how well SND as a provider of services to the Swedish research community fulfills its mission, focusing on the following general aspects:

- The scope of SND's mission
- SND's role in international cooperation
- SND as a facilitator for access to data
- SND's organization and personnel

Specific aspects to be addressed by the panel are indicated below (in no particular order):

#### **The scope of SND's mission**

At its establishment, SND was given an extensive mission. For example, within five years SND was to have complete information about Swedish databases in, especially, social medicine, the social sciences and the humanities, as well as a survey of corresponding databases in other countries. This is a very extensive mission. At the same time, lack of clarity prevailed on a number of legal issues relating to accessibility of research data that include information on individuals. The assessment should consider the extent to which the task given to SND:

1. Is reasonably balanced in relation to the resources that were provided.
2. Can be carried out with reference to existing legislation.

#### **SND's role in international cooperation**

Archiving research data and making such data accessible is to the highest possible degree an international activity that has great potential. The assessment should comment on:

3. How SND fulfills its role in international networks, collaborations and organizations.
4. To what extent SND is acting as a driving force in the international collaborations.

#### **SND as a facilitator for access to data**

SND's fundamental task is to make data accessible for research and teaching. Researchers and, where appropriate, students should simply and cheaply have access to data within SND's areas of responsibility. SND can meet this goal in several different ways. The traditional roles of a data archive are to store and document data and facilitate data access. SND can also obtain and supply data from other national archives through its international cooperation. SND can further contribute to increased data use by providing information about and access to data that is held by research groups and government authorities but that for various reasons cannot be held in SND's own archive. An assessment of SND should focus on how well:

5. SND's routines work for archiving, for providing quality assurance and for documenting existing research databases.
6. SND makes data accessible for research and how well SND produces and supplies data.
7. SND is surveying existing data within its areas of responsibility.
8. SND's research services function: consulting and providing information about existing data and other forms of support for researchers regarding data access, organization and use of large datasets.
9. SND functions as coordinator for data that are archived at different institutions, including universities, government agencies and international data archives.
10. SND performs its assignments within all three areas of responsibility, i.e. the humanities, the social sciences and medicine.
11. SND manages to clarify the legal aspects of storing data and making data accessible.

#### **SND's organization and personnel**

SND is a new organization that was placed at Gothenburg University in 2007. There is, however, a significant continuity with SND's predecessor, the Swedish Social Science Data Service (SSD) that was also located at Gothenburg University. In comparison to SSD, SND has a significantly more ambitious and broader assignment. SND has therefore continuously expanded its activities. The assessment should discuss:

12. How well SND's organization, expertise and personnel resources match SND's assignment.

13. To what extent SND's infrastructure (premises, equipment, etc.) is adequate for the assignment of SND.
14. If SND's organizational location in the present host university works well, and what measures if any of expertise, personnel, equipment etc. would be needed in order for the organization to better serve the research community.

The panel is also asked to report about any other scientific, administrative or financial issue which can be of importance for the Swedish Research Council.