

## **NEAR: The National E-infrastructure for Aging Research in Sweden.**

### Operational plan 2020

The National E-infrastructure for Aging Research in Sweden (NEAR) is financed by Vetenskapsrådet for the period 2018-2022. NEAR consists of 15 longitudinal databases with a focus on aging research that are included in a consortium of seven universities:

- Karolinska institutet; org. nr. 202100-2973, 171 77 Stockholm, ("KI");
- Blekinge Tekniska Högskola, org. nr. 202100-4011, 371 79 Karlskrona ("BTH")
- Göteborgs universitet; org. nr. 202100-3153, 405 30 Göteborg, ("GU");
- Stiftelsen Högskolan i Jönköping, org.nr: 826001-7333 Jönköping ("JU"),
- Lunds universitet, org. nr. 202100-3211, 221 00 Lund, ("LU");
- Umeå universitet, org. nr. 202100-2874, 901 87 Umeå, ("UmU");

In June 2019 Uppsala universitet, org. nr. 202100-2932, 751 05 Uppsala, ("UU") has been added as new member of the NEAR consortium

#### **Steering Board**

**Laura Fratiglioni**, Professor of Medical Epidemiology, Karolinska Institutet (Chair), **Anna Dahl Aslan**, Associate Professor in Gerontology, Jönköping University, **Sölve Elmståhl**, Professor of Gerontology, Lund University, **Carin Lennartsson**, Associate Professor in Sociology, Karolinska Institutet, **Lena Lewin**, PhD in Neurochemistry and Project Manager at Karolinska Institutet, **Gunnar Malmberg**, Professor of Human Geography, Umeå University, **Lars Nyberg**, Professor of Neuroscience, Umeå University, **Nancy Pedersen**, Professor of Genetic Epidemiology, Karolinska Institutet, **Johan Sanmartin Berglund**, Professor of Health Sciences, Blekinge Institute of Technology, **Marianne Schultzberg**, Professor of Clinical Neuroscience and Dean of Doctoral Education at Karolinska Institutet, **Ingmar Skoog**, Professor of Psychiatry, University of Gothenburg, **Anders Wimo**, Professor in Geriatric General Medicine, Karolinska Institutet, **Alicja Wolk**, Professor of Nutritional Epidemiology, Karolinska Institutet.

**Karl Michaëlsson**, Professor of Surgical Sciences, Uppsala University, is a new member of the SB, 2019.

Professor **Boo Johansson** (GU) has retired. GU has nominated **Linda Hassing**, Professor in Psychology, as his replacement.

#### **Primary purpose**

Our ultimate goal is to improve the health, care, and well-being of older people by optimizing a national integration of the major Swedish longitudinal, population-based projects on the health and care of older people. The new *National E-infrastructure for Aging Research* (NEAR) includes 15 databases derived from longitudinal cohort studies in different geographical areas in Sweden and currently available at seven universities. NEAR will facilitate the use of this existing large-scale collection of medical and social data by improving access and harmonizing the data. This in turn will enhance the quality and generalizability of aging research in Sweden, promote new national and international

collaboration, reinforce the international profile of Swedish aging research, and support the development of a new generation of qualified researchers.

### **Planned activities**

The planned activities will achieve the major objectives of NEAR, integrating the local databases in an efficient way while retaining their strength and data quality.

The full implementation of NEAR is divided into seven modules that define the activities needed to develop and run the e-infrastructure. Each module includes several tasks, requires staff, and needs a specific budget (for a detailed description of the modules, see the application). We plan to build and implement NEAR during the first 4-year period.

**Module 1.** Create an organization that will efficiently steer NEAR and ensure the direct participation of all the databases involved.

#### *Status:*

- In 2019 the Steering Board (SB) has appointed the Operational Group (OG). The OG is constituted by the NEAR scientific coordinator (D Rizzuto), a database manager (A Darin Mattsson), a data scientist (X Wu), a statistician (E Ripamonti), and a scientific communicator (L Sjöberg).
- The SB is working with the policies that will form the backbone of the entire infrastructure. The SB meets twice a year. The next SB meeting is planned for December 18<sup>th</sup>, 2019.

#### *Planned activities for 2020:*

- Finalize the policies at SB meeting.
- Starting in 2020, the SB will hold yearly meetings with the Advisory Boards (AB) Ethical AB, as well as with the Scientific and Societal AB.
- Professor Boo Johansson from Gothenburg University (GU) has retired. GU has nominated Professor Linda Hassing as his replacement in the SB. Decision will be taken by the SB during next SB meeting (Dec 18<sup>th</sup>).
- A substitute for the Scientific Communicator position will be hired for the year 2020 (the communicator is on parental leave).

**Module 2.** Building a national database with a dynamic design and an architecture that ensures data quality by preserving the autonomy and independence of the local projects. An electronic platform will run the network interface to receive queries, aggregate and distribute data, and maintain centralized logs of NEAR usage.

#### *Status:*

- The OG has established contact with the external supporters (Maelstrom and SND) which will provide technical support for NEAR implementation.
- The NEAR webpage ([www.near-aging.se](http://www.near-aging.se)) has been created.
- The documentation of databases in NEAR will be done by the end of 2019.

#### *Planned activities for 2020:*

- The OG will further development the NEAR webpage to create an interactive interface. The web platform will contain, in a homogeneous format, the documentation of all the 15 studied included in NEAR and an e-codebook that contains the

information about all the variables in each study. The e-codebook will be interactive, sortable, and have expandable levels of information. NEAR's users will thus be able to browse the material collected in the e-codebook (i.e., metadata and a list of variables in NEAR).

- The web-platform for the internet-based meta-database will be launched online.

**Module 3.** Documenting the baseline and follow-up information collected in the 15 projects, including data collection procedures, coding, and cleaning. Module 3 is interconnected with Module 2 and provides the basis for Module 4.

*Status:*

- The NEAR and local Database managers are translating local codebooks (from Swedish to English) and creating a meta-data codebook in collaboration with Maelstrom (<https://www.maelstrom-research.org/mica/network/near#/>). The documentation will be finished by the end of 2019.

*Planned activities for 2020:*

- The NEAR database manager will work closely with the local database managers to review the existing meta-database. In particular, he will ensure good documentation of any change across data collection waves (e.g., changes in lab references, measurement methods).

**Module 4.** Harmonizing data from the 15 datasets, which cover multidimensional medical, biological, social, and environmental information.

*Status:*

- Established contact and discussing how the support and training will proceed together with Maelstrom.
- The OG is exploring all possible methods of harmonizing data to establish simple and efficient harmonization procedures and necessary documentation for harmonization reproducibility. Although the harmonization is project-specific, the procedures are generalizable across the projects.

*Planned activities for 2020:*

- The coordinator and the database manager will attend courses about harmonizing procedure at Maelstrom in 2020.
- The first harmonization project will start in December 2019.

**Module 5.** Facilitating access to and pooling of the population-based datasets, which will increase the number of national and international users. This also includes helping users conduct meta-analyses or other integrated methods when harmonization is problematic.

*Status:*

- The SB is working with the data access procedures and aim to finalize the policy by December 2019.

*Planned activities for 2020:*

- More policies are needed and will be completed during 2020.
- The OG will start to provide user support to explain data access, resolve technical issues, and help users perform meta-analyses or analyses of integrated data.

**Module 6.** Maintaining and complementing the databases with follow-up data and enriching the existing databases by collecting new data.

*Status:*

- Six databases included in NEAR (the Betula Project, GENDER, Kungsholmen Project, Octo-Twin, SATSA, and SALT) have already completed data collection. For these databases, the NEAR database manager and the local database manager, will perform database maintenance and review/update the existing documentation from 2018 onward.
- SNAC-national started a new data collection 2019, January.

*Planned activities for 2020:*

- Nine databases in NEAR are still ongoing. The local database manager and PIs will continue to ensure that the data collection satisfies the same high standards used in NEAR so far.
- H70 and SWEOLD will start new data collections during 2020.

**Module 7.** Promoting and expanding NEAR.

*Status:*

- A symposium and an information desk was held at the IAGG-ER conference in Gothenburg, 2019.
- An internal scientific workshop for possible collaboration was held in May 2019.
- NEAR was promoted in the “Optimising Multistudy Integrative Research” conference in Cambridge, 2019.
- NEAR was presented in the SWEAH conference in Lund, 2019.

*Planned activities for 2020:*

- An information desk and symposium is being planned at NKG Iceland 2020
- An internal workshop with focus on integrative data analysis methods are being planned (as a request from previous workshop).
- NEAR will be presented for the Karolinska Institutet research committee December, 2019.
- NEAR will be presented at the VR seminar for infrastructures in September, 2020.