

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

Operational plan

The National E-infrastructure for Aging Research in Sweden (NEAR) is financed by Vetenskapsrådet 2018-2022. NEAR includes 15 longitudinal databases with a focus on aging research and is supported by a consortium of six 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");

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) will initially include 15 databases derived from longitudinal cohort studies in different geographical areas in Sweden and currently available at six 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 added value of NEAR is described in the *Strategic Plan*.

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 2018 the Steering Board (SB) has appointed the OG. The OG is constituted by the NEAR coordinator, a database manager, a data scientist, and a scientific communicator.
- The SB is working with the policies. The first SB meeting has been done in March and the next is planned for December 3rd, 2018.

Planned activities:

- In 2019 a Statistician will be recruited and the AB's will be appointed.
- Finalize the policies by April 2019.
- Review, finalize, and approve the NEAR architecture (**Figure 1**) proposed by the OG by Mar 2019
- Starting in 2019, the SB will hold yearly meetings with the Ethical AB, as well as with the Scientific and Societal AB.

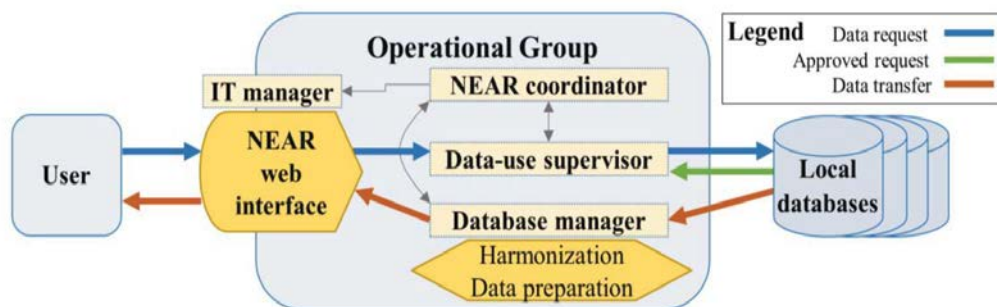


Figure 1. Architecture of the NEAR e-infrastructure

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).
- The NEAR webpage (www.near-aging.se) has been created.

Planned activities:

- The OG will ascertain the differences in data storage methods, variable identification, and coding at the participating centers. Specifically, the OG will a) ensure that all participating centers have compatible hardware and software, b) evaluate the security requirements at each site to determine the steps needed for data transfer between the individual centers and the database management group, c) explore other steps needed to establish a simple and efficient Internet-based meta-database, and d) consult with local database managers during the development of the e-codebook. At the same time, the OG will design/define the NEAR architecture to be finalized and approved by the SB.
- In 2019 The OG will further development the NEAR webpage to create an interactive interface.

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 OG (IT and database managers) have started to interact with the local database managers to outline the procedures for maintaining the completed and ongoing

databases. The first meeting with the local database managers has been done in June 2018

- The NEAR DM and the 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#/>).

Planned activities:

- Finalize the procedures for maintaining the completed and ongoing databases. The second meeting with the local databases managers is planned for December 6th 2018.
- The NEAR database manager will work closely with the local database managers to review the existing meta-database and ensure that the description is consistent across different databases. In particular, he will ensure that all documentation is in English; that there are codebooks for each data collection wave and records of any change across data collection waves (e.g., changes in lab references, measurement methods); and that there is a description of the reference population, a description of the sample, a baseline non-participation rate, and an attrition description.

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.

Planned activities:

- The coordinator and the database manager will attend courses about harmonizing procedure at Maelstrom in 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.

Planned activities:

- In 2019 the data access procedures will be finalized. The procedures will determine the technical platform of the web interface (Module 2) and will include a detailed description of: a) how to submit a research proposal to NEAR; b) the NEAR internal approval process; c) the review process for ethical permits; d) how to track the approval process and how to provide a record of this process after its completion; e) the timeline for the data access process (project approval, data harmonization); f) the cost of data access (the fee will cover NEAR data processing and management); g) possible formats of the data to be provided to the users; h) authorship, copyright, and intellectual property rights; i) NEAR acknowledgment; and j) user support.

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.

Planned activities:

- 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.

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

- A symposium, evening event, and an information desk are being planned for the IAGG-ER conference in Gothenburg, 2019.

Planned activities:

- The scientific communicator is organizing a Scientific workshop for May 2019