

The National E-infrastructure for Aging Research (NEAR).

Operational plan 2022

NEAR is organized as a consortium, defined and regulated by the Consortium agreement already approved (diary numbers: 2-493/2017 and 2-4450/2020). The consortium includes eight Universities: Karolinska Institutet, the Universities of Umeå, Jönköping, Gothenburg, Lund, Uppsala, and Stockholm; and the Blekinge Institute of Technology.

NEAR is currently led by a Steering Board (SB) appointed by the eight university-members of the consortium (**Figure**). The SB comprises a chair and one representative for each of the NEAR databases. They are all well-known researchers in the field of aging and health. Associated members include the NEAR Director, a representative from the KI's Board of Research, as well as the NEAR Database Coordinator and Scientific Communicator. The SB members will serve for the entire period. Retiring board members will be replaced by their respective university. According to the *Consortium agreement*, the SB has full decision-making power and has the following responsibilities: (1) Report to KI's president, the Parties, and the Swedish Research Council; (2) Guarantee that the infrastructure is developed and run in line with goals and deliverables expressed in the application; (3) Ensuring adherence to legal requirements (confidentiality and safety regulations); (4) Ensuring adherence to policy; and (5) Approval of the strategic plan and annual budget. The SB has established three Advisory Boards (AB): the Societal (SoAB), Scientific (ScAB), and Ethical (EAB). They include distinguished specialists who play key roles for societal, ethical, and scientific matters.

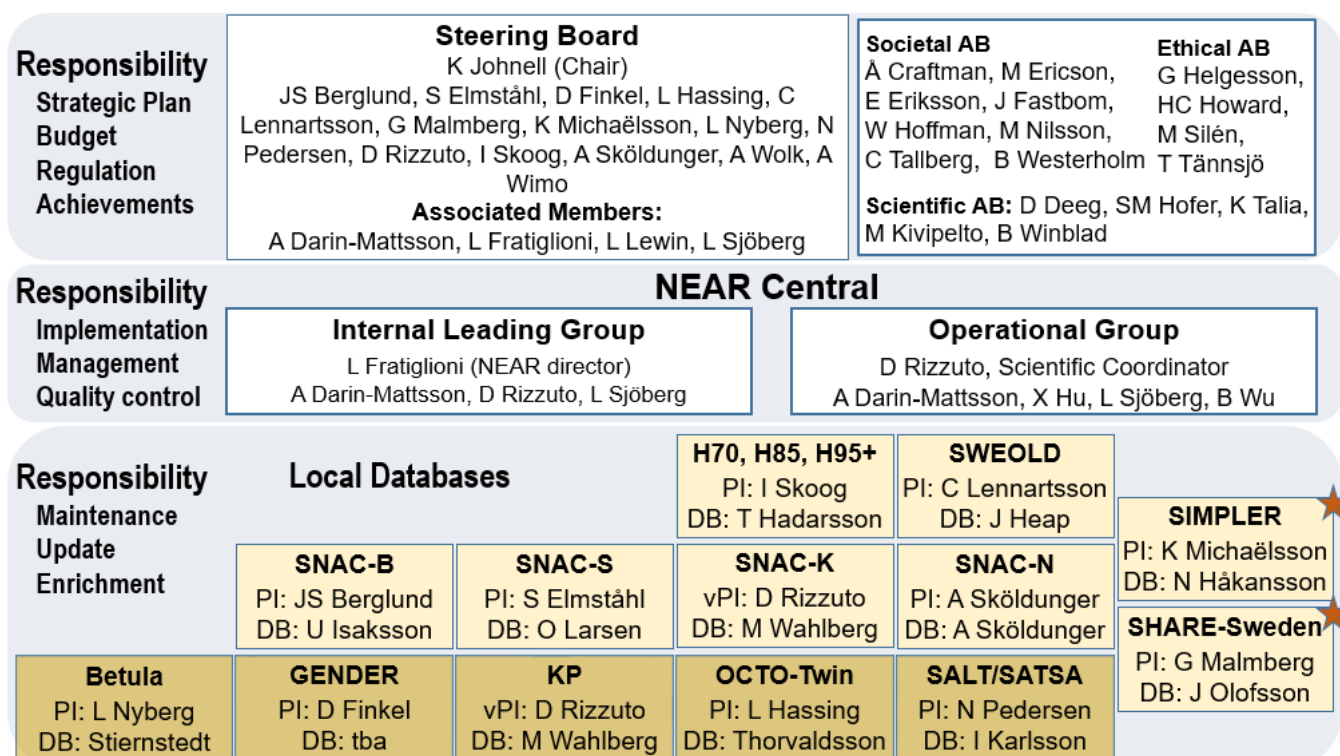


Figure. Current organization and architecture of NEAR.

Local databases: GENDER: Ageing in Women and Men: A Longitudinal Study of Gender Differences in Health Behaviour and Health among Elderly; H70 H85 and H95+: Gothenburg Birth Cohort Studies; OCTO-Twin: Origin of Variances in the Oldest-Old: Octogenarian Twins; SALT: Screening Across the Lifespan of Twins; SATSA: The Swedish Adoption/Twin Study of Aging; SNAC: Swedish National Study on Ageing and Care; KP: Kungsholmen Project; SWEOLD: Swedish Panel Study of Living Conditions of the Oldest Old.

★ SHARE-Sweden (Survey of Health, Ageing and Retirement in Sweden) and SIMPLER (Swedish Infrastructure for Medical Population-Based Life-Course and Environmental Research) are marked with a star as they also are part of other infrastructures. A darker background color is applied for projects with completed follow-up.

Abbreviations: AB: Advisory Board, PI: Principal Investigator, DB: Database Manager.

The current organization meets the following requirements: (1) creation of a dynamic database structure in which the original data remain at the local centers to ensure high data quality, (2) creation of a single network portal to receive and distribute queries, aggregate and distribute data, and maintain centralized user logs (NEAR-Central), and (3) promotion of NEAR by increasing the number of national and international users.

Primary purpose

NEAR's purpose is to empower aging research in Sweden by promoting high-quality research and giving substantial added values to the research field. This will contribute to the identification of sustainable intervention strategies for better health and care for older people. To this end, NEAR is harmonizing existing databases from major population-based longitudinal cohorts on health and aging in Sweden, and making project-specific datasets usable and available to the research community as well as public health and private sectors.

Planned activities

The planned activities will achieve the major objectives of NEAR by integrating the local databases in an efficient way while retaining their strength and data quality. The implementation of NEAR is currently ongoing and follows the planned activities without any substantial deviation. The full implementation of NEAR is divided into seven modules that define the activities needed to develop to 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 with diary number: 2017-00639).

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

Tasks	Description	Status	Planned activities for 2022
Task 1	Finalize the organizational structure of NEAR.	Done	
Task 2	Outline the NEAR policies.	In progress	The OG group is working with the KI legal office for the implementation of a unique Data Transfer Agreement (DTA) and Data Process Agreement (PDA) for NEAR.
Task 3	Finalize the NEAR architecture.	Done	
Task 4	Annual meetings with the SB and biannual meetings with the ABs.	Done	Meetings with the SB and AB will continue as planned.

Note:

New Board members: In the spring of 2021 Deborah Finkel was elected as the new Principal Investigator (PI) and representative of GENDER, and Anders Sköldunger as the new PI and representative for SNAC-N.

New members of the OG: A new NEAR Statistician, Bolin Wu, was hired and started to work for the OG by 11 October. He is replacing Enrico Ripamonti, who left the OG in the summer of 2021.

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.*

Tasks	Description	Status	Planned activities for 2022
Task 1	Contacts with external supporters for provision of technical support.	Done	The collaborations with Maelstrom, the Swedish National Data Service (SND), Swedish National Infrastructure for Computing (SNIC), and Swedish University Computer Network (SUNET) will continue as planned.
Task 2	Finalize the design of the NEAR architecture.	Done	Maintenance of the NEAR architecture will continue as planned.
Task 3	Creation of the NEAR web platform for browsing of meta-data.	Done	The data documentation, e-codebook and NEAR platform are constantly being updated.
Task 4	User data access via the NEAR web platform.	In progress	All data access activities (i.e., variable search, user queries, data application etc.) will be accessible at the NEAR platform and centralized logs of NEAR usage will be maintained.

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.*

Tasks	Description	Status	Planned activities for 2022
Task 1	Outline procedures for maintenance of the local databases.	Done	Newly collected data will be documented and presented as planned.
Task 2	Production of uniform local metadata and NEAR documentation.	Done	
Task 3	Documentation of existing linkage to registry.	Done	
Task 4	NEAR-Register Utilizer Tool (RUT) interoperability.	In progress	Initial meetings with RUT will take place.

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

Tasks	Description	Status	Planned activities for 2022
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Task 1	OG training in harmonization.	Done	
Task 2	Procedures for data harmonization.	Done	
Task 3	Harmonization of data and documentation.	In progress	To facilitate harmonization of future research projects, basic level harmonization for certain core variables, e.g., education will be created and stored in a specific database. Harmonized variables will be documented and presented as e-codebooks on the NEAR platform. Harmonization will be an ongoing activity that is performed on demand.

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.*

Tasks	Description	Status	Planned activities for 2022
Task 1	Development of data access procedures.	In progress	The SB and the OG are working together with the KI legal office to finalize the data access procedures including Data Transfer Agreement (DTA), Data Processing Agreement (DPA), and Service Agreement (SA).
Task 2	Provision of user support.	Done	The OG will continue to provide user support to explain data access, resolve technical issues, and help users to perform harmonization, meta-analyses, or analyses of integrated data.
Task 3	Outline of the NEAR performance metrics.	In progress	Measures will be developed to quantify NEAR's scientific impact in Sweden and internationally and to track the use, impact, and results of the research projects using NEAR data.

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

Tasks	Description	Status	Planned activities for 2022
Task 1	Maintenance of the local databases.	Done	
Task 2	Collection of new data and updated documentation.	Ongoing	Nine databases in NEAR are still ongoing. The PIs and local database managers will continue to ensure that the data collection satisfies the same high standards used in NEAR so far.

			SNAC-national, SHARE-Sweden, SWEOLD, and the Gothenburg H70 Birth Cohort Studies will collect data during 2022.
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Module 7. Promoting and expanding NEAR.

Tasks	Description	Status	Planned activities for 2022
Task 1	Development of NEAR courses for users.	In progress	NEAR courses will be developed and recorded, and training for users will continue as planned.
Task 2	Expansion of NEAR.	In progress	Criteria will be established to facilitate the inclusion of additional databases in NEAR.
Task 3	Communication with the public.	Ongoing	The NEAR homepage (https://www.near-aging.se) and popular science descriptions of the major reports and scientific articles from projects using NEAR data will continually be updated. A newsletter will be drafted.
Task 4	New collaborations.	Ongoing	Increased collaborations with similar international consortia, i.e., Integrative Analysis of Longitudinal Studies of Aging (IALSA), as well as continued collaboration with the private sector will take place.
Task 5	Organization of kick-off and workshops.	Ongoing	Annual NEAR workshops on methodological or scientific matters will continue as planned.