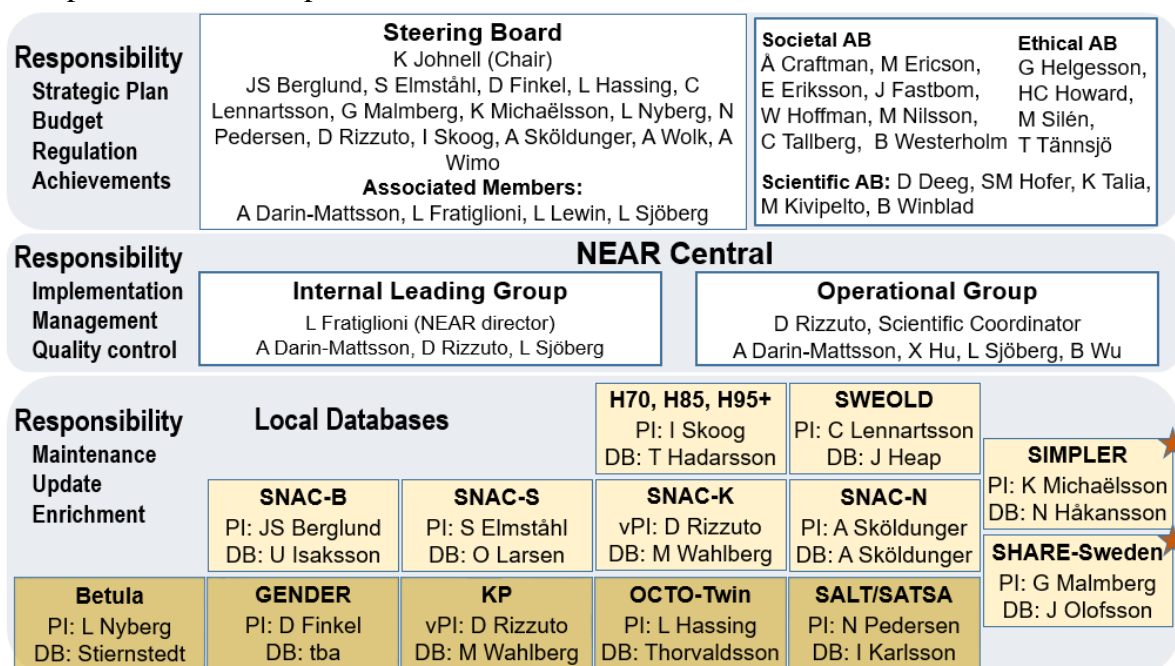# The National E-infrastructure for Aging Research (NEAR).
Operational plan 2023

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 1**). 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 until December 2022. From January 2023 a new organization will take place as depicted in **Figure 2**. The new organization will: a) decide on strategic issues concerning NEAR: operations (including finances and organization), by determining the annual reports according to the application and following proposals from the internal management team. b) determine governing documents for NEAR's operations, e.g., for: prioritizing access to the infrastructure, making available research data and software developed at/with the help of the infrastructure.

Responsibility	Steering Board	Societal AB	Ethical AB
Strategic Plan **Budget** **Regulation** **Achievements**	K Johnell (Chair) JS Berglund, S Elmståhl, D Finkel, L Hassing, C Lennartsson, G Malmberg, K Michaëlsson, L Nyberg, N Pedersen, D Rizzuto, I Skoog, A Sköldunger, A Wolk, A Wimo **Associated Members:** A Darin-Mattsson, L Fratiglioni, L Lewin, L Sjöberg	Å Craftman, M Ericson, E Eriksson, J Fastbom, W Hoffman, M Nilsson, C Tallberg, B Westerholm **Scientific AB:** D Deeg, SM Hofer, K Talia, M Kivipelto, B Winblad	G Helgesson, HC Howard, M Silén, T Tännsjö

NEAR Central

Responsibility	Internal Leading Group	Operational Group
Implementation **Management** **Quality control**	L Fratiglioni (NEAR director) A Darin-Mattsson, D Rizzuto, L Sjöberg	D Rizzuto, Scientific Coordinator A Darin-Mattsson, X Hu, L Sjöberg, B Wu

Local Databases

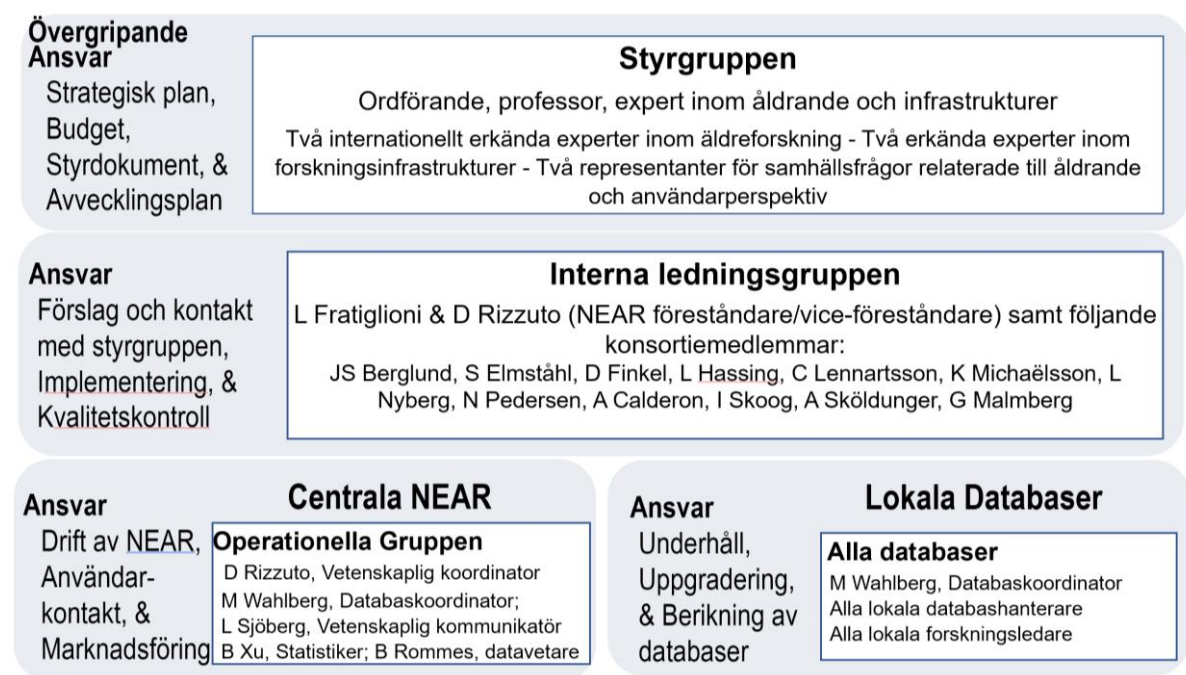| Responsibility			H70, H85, H95+ PI: I Skoog DB: T Hadarsson	SWEOLD PI: C Lennartsson DB: J Heap	
Maintenance **Update** **Enrichment**	SNAC-B PI: JS Berglund DB: U Isaksson	SNAC-S PI: S Elmståhl DB: O Larsen	SNAC-K vPI: D Rizzuto DB: M Wahlberg	SNAC-N PI: A Sköldunger DB: A Sköldunger	⭐ SIMPLER PI: K Michaëlsson DB: N Håkansson
	Betula PI: L Nyberg DB: Stiernstedt	GENDER PI: D Finkel DB: tba	KP vPI: D Rizzuto DB: M Wahlberg	OCTO-Twin PI: L Hassing DB: Thorvaldsson	SALT/SATSA PI: N Pedersen DB: I Karlsson
					⭐ SHARE-Sweden PI: G Malmberg DB: J Olofsson

Figure 1. 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.

Figure 2. NEAR organization and architecture from January 2023.

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 2023
Task 1	Finalize the organizational structure of NEAR.	Done	
Task 2	Outline the NEAR policies.	Done	The NEAR's policies will be revised and approved by the new SB.

Task 3	Finalize the NEAR architecture.	Done	
Task 4	Annual meetings with the SB and biannual meetings with the ABs.	Ongoing	Meetings with the SB and AB will continue as planned.

Note:
New members of the OG: A new NEAR Data Scientist, Basile Rommes, was hired and started to work for the OG.

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 2023
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.	Done	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 2023
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	RUT is not yet available – it is still in the developing phase

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

Tasks	Description	Status	Planned activities for 2023
Task 1	OG training in harmonization.	Done	
Task 2	Procedures for data harmonization.	Done	
Task 3	Harmonization of data and documentation.	Ongoing	To facilitate harmonization of future research projects, basic level harmonization for certain core variables, e.g., education is created and stored in a specific database. Already, harmonized variables are documented and presented as e-codebooks on the NEAR platform. In 2022 we have accelerated the data harmonization by recruiting three new staff, using part of the budget originally planned for in person-meetings/conferences (cancelled during the outbreak). The recruited staff will continue working with data harmonization during 2023 to complete the task. 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 2023
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.	Ongoing	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.	Done	

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 2023
Task 1	Maintenance of the local databases.	Ongoing	In 2022 extra staff (nurses and physicians) are in place to carry out the data collection that was cancelled due to the pandemic. The already recruited staff will complete this task during 2023.
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 2023.

Module 7. Promoting and expanding NEAR.

Tasks	Description	Status	Planned activities for 2023
Task 1	Development of NEAR courses for users.	Ongoing	NEAR courses are for users are done periodically on demand.
Task 2	Expansion of NEAR.	In progress	From 2023 two new databases will be included in NEAR. Moreover, linkage with quality registries such as SWEDEM will be done. The expansion of the existing databases will continue by linking the data with national registries.
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.
Task 4	New collaborations.	Ongoing	Increased collaborations with similar international consortia (i.e., Integrative Analysis of Longitudinal Studies of Aging (IALSA)) with national infrastructures (i.e., REWHARD), as well as collaborations with the private sector has started.
Task 5	Organization of kick-off and workshops.	Ongoing	Annual NEAR workshops on methodological or scientific matters will continue as planned.