

Summary

This report was collaboratively drafted by NEAR's Operational Group and Internal Leading Group and approved by the Steering Group. In 2023, NEAR entered its expansion and promotion phase, marked by several activities at different levels.

Expansion activity: 1) Recruitment of 3 new members: a Scientific Promoter and 2 Project Coordinators; 2) Inclusion of 2 new databases located at Umeå University: the Swedish national inventory of health and care (SWENIS) and Sheltered Housing (TRYBO); and 3) Increase of users number for collaborative projects up to 41 and delivery of 330 harmonized variables.

Promotion activity: 1) Creation of a biannual newsletter; 2) Development of new communication materials; and 3) Organization of several scientific meetings.

Scientific activity: 1) Two symposiums at national and international conferences and 2) A seminar titled "Ethical Perspectives on Data Usage in Research Infrastructures", co-arranged with the Comparative Research Center Sweden (CORS), held at Karolinska Institutet (KI).

Scientific output: 1) 10 new projects were initiated; 2) 15 studies were published in peer-reviewed journals, and 3) One report and four theses were completed.

First high-impact products: 1) *Clinical impact*- development of clinical health charts for older adults through a NEAR project, which can be used in primary care after ongoing validation, and 2) *Scientific impact*- development of statistical models to be used when harmonization across different local databases is not feasible.

Popular science description

NEAR promotes and supports aging research by facilitating the use of longitudinal population-based data from renowned Swedish cohort studies on aging and health. NEAR operates through a collaboration among eight Swedish universities. It encompasses 15 databases containing comprehensive biomedical, clinical, social, and psychological health data from around 90,000 older adults followed for 12 to 52 years. NEAR collaborates with the Survey of Health, Ageing and Retirement in Europe-Sweden (SHARE-Sweden) from the CORS infrastructure. NEAR's mission is to support high-quality aging research by providing big health data while maintaining the same quality and richness as in single population-based studies.

Description of operations and activities

In 2023 NEAR made significant progress mostly in line with the original timeline as described below.

Time plan. We have followed exactly the time plan provided in our application in 5 modules:

Modules 3-6, and 9 (database documentation and harmonization, increasing visibility and users, enrichment of data collections, and evaluation and knowledge gaps) (see: "Updated GANNT schema_2023").

Small deviations occurred in the following modules: **Module 1** (organization and governance): The newly formed Steering Group met 3 times instead of 2. Moreover, Database Managers held only one formal meeting instead of two. The second formal meeting was replaced by continuous dialogue and virtual meetings when needed. Also, after a trial period, the Operational Group and Database Managers decided to use e-mail and platforms, such as Teams, for communication, which was the fastest and most effective way. Finally, the Operational Group expanded with three members. Uppsala University has not yet signed the consortium agreement – the discussion is ongoing.

Module 2 (completing the technical platform): The development of a technical environment, to safely carry out online data analysis, will start in 2024. **Module 7** (expanding and including new databases) and **Module 8** (user support and knowledge advancement): NEAR are ahead of schedule since meetings with potential future databases and one implementation of findings already occurred in 2023 (see: "methodology development").

Design, development, and operation of the infrastructure

– *Indicate how the modules individually and, if relevant, jointly contribute to the achievement of scientific objectives.*

To fulfill NEAR's scientific objectives, each module plays a crucial role, independently and collaboratively, in investigating the social, biomedical, and psychological aspects of aging and health throughout the lifespan.

Module 1 establishes the efficient organization and daily operations of NEAR, which is the foundation for fulfilling NEAR's scientific missions.

Module 2 ensures a functioning and efficient technical platform, crucial for maintaining data quality, security, and accessibility. The platform is essential for NEAR's research infrastructure's seamless operation, facilitating data identification, management, and analysis.

Module 3 establishes the foundation of NEAR's technical platforms by assembling database documentation and meta-data. This documentation ensures transparency and facilitates efficient data identification across various databases.

Modules 4 and 9 are intricately intertwined and indispensable for NEAR's scientific pursuits. Module 4 focuses on harmonizing data across NEAR cohorts, a critical aspect of conducting meaningful analyses and drawing reliable conclusions. Module 9 provides user support, indispensable for researchers navigating NEAR's complex datasets and technical platforms. This ensures optimal resource utilization and scientific support.

Module 5 focuses on increasing NEAR data visibility to attract a broader user base. Enhanced visibility facilitates the dissemination of research findings and fosters collaboration among researchers. Through various communication and outreach activities, NEAR aims to engage a diverse audience and promote its rich and unique dataset for advancing scientific knowledge and improving older adults' lives.

Module 6 emphasizes the enrichment of participating databases' data collection. This enhances NEAR's capacity to address emerging research tracks related to aging biology, clinical complexity, and social and physical conditions. In 2023, more extensive biological analyses of already collected serum and/or information on social isolation and vaccinations were included in the follow-up examinations of four databases. This enables researchers to explore new avenues of inquiry and deepen their understanding of aging-related phenomena.

Modules 7 and 8 expand NEAR's research scope by incorporating additional databases like SWENIS and TRYBO. These expansions broaden NEAR's investigative purview, particularly concerning care requirements during normal and critical periods. NEAR's ultimate vision is to identify sustainable interventions and implementations for better health and care for older adults. Modules 2, 3, 4, and 8 helped achieve this goal in 2023 through NEAR findings. In detail, clinical health charts for older adults were developed through a NEAR project, which can be used in primary care (see: "methodology development and developmental work").

Module 9 is instrumental in advancing NEAR's objectives by innovating survey techniques for older populations, developing smartphone apps for data enrichment, and introducing accelerometers to assess physical activity and sleep patterns. Additionally, it spearheads methods development for blood-based biomarkers, harmonizes diagnoses, and explores machine learning for enhanced consistency across NEAR databases, ensuring cutting-edge research and personalized healthcare insights.

– *Describe the status of procurement and development of equipment if covered by the grant.*

During the year, the procurement of an updated service agreement with Maelstrom Research, which provides the foundation for NEAR's interactive e-codebook and harmonization process, occurred.

– *Describe how new equipment is made available and used:*

The NEAR platform is consistently updated to ensure optimal functionality and user experience for NEAR's community.

– *Describe methodology development and other development work conducted during the year.*

Significant methodology development and other developmental work propelled NEAR's progress:

Data enrichment: Swedish National Study on Aging and Care (SNAC) – Kungsholmen, Nordanstig, Blekinge, and Skåne: Follow-up examinations commenced for those aged 72 years and above for wave 8. For SNAC-K, SNAC-S, and SNAC-B, the examinations of the new cohort of 60-year-olds continued for wave 8. SNAC-K underwent database expansion, including updated linkages to vital registries and a specific enrichment of the data collection including a more extensive biological analysis of already collected serum from SNAC-K.

NEAR enrichment: To expand NEAR, we met with the Principal Investigators of the Uppsala Longitudinal Study of Adult Men (ULSAM) and the Healthy Ageing Initiative (HAI), Uppsala University; Epidemiology for Health (EpiHealth), Lund University; and the Swedish registry for cognitive/dementia disorders (SveDem), Uppsala University.

Method development: NEAR coordination has developed complex probability models for harmonizing data across databases, addressing missing data challenges, and optimizing data use

Legal development: In 2023, legal compliance underwent extensive development. In detail, the Data Transfer Agreement (DTA) within Europe, and outside Europe, and the internal Research Collaboration Agreement (RCA) were drafted by the Operational Group and the consortium members' legal offices.

Development of Innovative Tools: A project including four NEAR databases has been used to create health charts by developing a health assessment tool (HAT) for the older population. In 2023, as part of a pilot project, the HAT was implemented in five primary care facilities across Sweden; three in Stockholm, one in Kalmar, and one in Nordanstig. Data collection assessed 800 patients. Interviews with primary care personnel were also conducted.

Communication development: During the past year, the NEAR newsletter was launched, including the latest news and activities from NEAR. Currently, the newsletter has around 500 recipients. Since May 2023, various communication materials related to NEAR have also been created and developed, such as 1) an updated NEAR folder, which can be used when promoting NEAR in academia and non-profit organizations; 2) an illustration to present a visual overview of NEAR; 3) Creation of a NEAR X-account; 4) a promotion plan to initiate collaboration and stimulate data use in private profit organizations.

Collaboration with other infrastructures

1. NEAR expanded its collaboration with key national infrastructures by promoting and attending two meetings with CORS; Relations, Work and Health across the life-course – A Research Data Infrastructure (REWHARD); Swedish population databases for research (SWEDPOP); SIMPLER; Evaluation Through Follow-up (UGU); and Swedish Twin Registry (STR).
2. A seminar on “Ethical Perspectives on Data Usage in Research Infrastructures” co-hosted by NEAR and CORS, attracted over 100 participants, facilitating discussions on ethical considerations in utilizing secondary data for research across various sectors.
3. Internationally, NEAR engaged with the Integrative Analysis of Longitudinal Studies of Aging and Dementia (IALSA), Effects of Low-level Air Pollution – a Study in Europe, (ELAPSE), UK-Biobank, and Longitudinal Study of Aging Danish Twins (LSADT), resulting in joint publications.

Data management and the need for e-infrastructure support

NEAR has a data management plan that aligns with the FAIR Guiding Principles for Scientific Data Management and Stewardship. By adhering to FAIR principles, NEAR aims to maximize the impact and value of its data assets. This fosters collaboration, innovation, and scientific discovery across diverse disciplines and communities.

Documentation and e-codebook. Collaboration with Maelstrom Research is facilitated to keep its interactive e-codebook updated. Meta-data documentation for the two newly added databases, SWENIS and TRYBO, is ongoing. NEAR has also described and documented the NEAR databases on the SND Data Organisation and Information System (DORIS), launched by the Swedish National Database Service (SND), ensuring comprehensive data description and accessibility.

Data management. An annual workshop and regular meetings brought together 10 Database Managers led by a Database Manager Coordinator. They addressed overarching database management issues and explored topics such as open access, data sensitivity, and legal compliance. The workshop resulted in a Zoom meeting with KI's Data Access Unit (DAU) and SND to discuss these issues further. In addition, the Operational Group actively assisted a local database with data documentation, cleaning, and warehouse creation. This was done utilizing a secure MySQL relational management database system hosted on the server at ARC (see below).

Empowering the NEAR Platform. Collaboration with the National Academic Infrastructure for Supercomputing in Sweden (NAISS), led to the establishment of a MySQL database at ARC to meet NEAR’s evolving needs. Ongoing updates to the NEAR platform, powered by the open-source software OBiBA for Epidemiology, ensure robustness and reliability, with regular backups conducted on the server located at ARC. These efforts underscore NEAR’s commitment to maintaining high standards of data management and infrastructure support for research in aging and health.

Changes in the organization

NEAR underwent significant organizational changes to enhance its structure and capabilities:

1. A newly appointed Steering Group was established, comprising members renowned for their expertise in aging research, research infrastructures, and societal issues related to aging, ensuring diverse perspectives. Led by Björn Halleröd, Professor in Sociology at the University of Gothenburg, the Steering Group includes Wilhelmina Hoffman, MD, Geriatrician, and President of the Swedish Dementia Centre; Anne Ekdahl, MD, Geriatrician, and Senior lecturer at Lund University; Luigi Ferrucci, MD, Scientific Director of the National Institute on Aging; and Kaare Christensen, Professor of Epidemiology at the University of Southern Denmark. The Operational Group was expanded by including Davide Vetrano, MD, PhD as Scientific Promotor (30%), alongside Project Coordinators Ingrid Ekström, psychologist, PhD (25%) and Ulrika Isaksson, computer scientist (20%) reinforcing NEAR’s possibilities to achieve the planned goals in research and innovation in aging studies.
2. Two NEAR cohorts (COSM and SMC) expressed intent to withdraw from the consortium agreement, which prompted ongoing dialogues and a collaboration agreement. The addition of two new databases in 2023 signifies efforts to mitigate potential cohort withdrawals.

Work of the Steering Group

The Steering Group has decision-making power, assuming full responsibilities for the following key issues: 1) Report to KI’s president, the Parties, and the Swedish Research Council (VR); 2) Guarantee that the infrastructure is developed and run in line with goals and deliverables expressed in NEAR application and Agreement with VR; 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. Throughout 2023, three meetings were held. The main matters discussed in the meetings were collaborations with other infrastructures, ethical issues, activities related to promotion and expansion, and the budget.

Economic outcome

Approximately 60% of the budget received was used as planned. The unutilized amount of around 11 million SEK (40%) can be attributed to specific factors outlined in the table below. The other cohorts deviated marginally from planned activities.

Description	Amount (tSEK)	Actions
NEAR – Central		
Delay in recruiting the Statistician and Research Assistant	2120	The recruitment process is ongoing
Delay in agreement with Swedem	350	The agreement is under review at the KI legal office
Delay in agreement with Malmstrom, SUNET, and NAISS	800	The agreement with Malmstrom was signed in March 2024
Linkage with National registries	400	Process ongoing
NEAR - Local		
SWEOLD - Delay in the new data collection	2000	Data collection has started and will be finalized in 2024
H70 - Delay in the new data collection	1800	Data collection has started and will be finalized in 2024

Comments on key figures

The total number of NEAR applications has been stable, 11 in 2022 and 10 in 2023. On the other hand, NEAR data users have increased from 30 in 2022 to 60 in 2023. Moreover, the number of variables delivered has increased from 8258 in 2022 to 34 688 in 2023. For more details about 2023 publications and users' sex distribution compared to 2022, see the headings: "Comments on the publication list" and "Equality".

Comments on the publication list

In 2023, NEAR achieved notable output by publishing 15 peer-reviewed articles on collaborative projects including 2 or more datasets, one report, and four PhD theses. This marks an increase compared to 2022, with six additional outputs produced (two articles, four theses, and one report). Particularly encouraging is the integration of NEAR data into PhD theses highlighting the vital role of emerging scholars in aging research. In 2023, scientific productivity at the local level remains as impressive as in previous years: 144 peer-reviewed articles, 4 reports, and 10 PhD theses.

Equality

As mentioned in the gender equality plan, NEAR has more women than men employed, both centrally and locally. NEAR actively recruited more men to the Operational Group in 2023, including one male Scientific Promoter and a male Statistician on a permanent contract. Regarding data request applications, NEAR had an even sex distribution of PIs and co-applicants in 2022 and 2023. Positively, the sex distribution of PIs of published projects became more even in 2023 than in 2022. Every year, NEAR reviews the sex distribution of personnel and addresses any deviations in upcoming recruitments.

Risk analysis

Risk analysis for NEAR in 2023 identified two areas of concern:

Turnover of NEAR leaders. As the NEAR Director and some PIs approach retirement, strong internal replacement candidates have already been identified. However, full attention will be devoted to succession planning in 2024.

Recruitment problems. NEAR requires highly specialized staff that can be difficult to recruit or keep in competition with other employers, such as the industry. Actions are underway to address recruitment difficulties effectively.

Training, outreach, and user support

In 2023, NEAR made significant strides in training, outreach, and user support:

- The NEAR Operational Group provided guidance and support to users across 15 projects, facilitating data requests, delivery, and harmonization. The Operational Group held an open R workshop at Karolinska Institutet, to improve users' statistical proficiency.
- Members of the Operational Group attended advanced statistics courses at the Swiss Epidemiology Winter School & the Summer School on Modern Methods in Biostatistics and Epidemiology in Italy.
- NEAR presence was showcased at various conferences including the European Geriatric Medicine Society congress in Finland; the National Graduate School on Ageing and Health conference in Sweden; BETULA day at Umeå University; and a seminar on individual-based databases at Lund University. A poster was also presented during the KI core facility lunch.
- NEAR's online visibility has been robust with 687 visitors on the homepage between September 19 and December 31, 2023, and 1935 views on X since the first post on August 24, 2023, reflecting growing interest and engagement in NEAR's resources and activities.

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