NEAR - Annual Report 2024

SUMMARY

This report was collaboratively drafted by NEAR's Operational Group and Internal Leading Group and approved by the Steering Group. In 2024, NEAR continued its expansion and promotion phase, marked by several activities at various levels.

Regarding **expansion**, a Statistician/Database Coordinator and two Project Coordinators joined NEAR. An agreement was also established with Uppsala University to include two new cohorts into NEAR: the Uppsala Longitudinal Study of Adult Men (ULSAM) and the Healthy Ageing Initiative (HAI). Additionally, the total number of collaborative projects started increased to 49, and 309 harmonized variables were delivered.

In terms of **promotion** and **scientific engagement**, NEAR organized two symposiums at international conferences and was present or showcased at five additional conferences. NEAR and research findings were also presented at three universities and during public health days in Nordanstig municipality. To enhance visibility and outreach, a LinkedIn account was also created.

Scientific output remained strong, with 13 projects initiated, 16 studies published in peer-reviewed journals, and two theses completed.

POPULAR SCIENCE DESCRIPTION

NEAR advances aging research by facilitating access to high-quality longitudinal population-based data from renowned Swedish studies on aging and health. Operating through a collaboration among seven Swedish universities, NEAR integrates 15 databases with individual assessments and actively collaborates with national and international research infrastructures.

The mission of NEAR is to support high-quality aging research by providing comprehensive health data while preserving the depth and richness of single population-based studies. NEAR also strives to foster national and international collaborations, enhancing the quality and generalizability of research findings. NEAR offers a wide range of biomedical, clinical, social, and psychological health data from more than 90,000 older adults, who have been followed for 12 to 52 years.

DESCRIPTION OF OPERATIONS

In 2024, NEAR made significant progress, mainly in line with the original timeline outlined below.

1. Time plan

NEAR has followed the timeline set in our application in six modules: Modules 3-7 and 9, covering database documentation and harmonization, increasing visibility and user engagement, new data collection and databases inclusion, user support and knowledge advancement, and evaluation of knowledge gaps (see "Updated GANNT schema_2024"). Minor deviations occurred in the following modules:

- **Module 1** (organization and governance): The Steering Group met once instead of twice, as continuous dialogue replaced the second formal meeting when necessary. The Internal Leading Group, however, met twice instead of once. According to the time plan, the Operational Group expanded to include a Statistician. However, it also expanded with two Project Coordinators.
- **Module 2** (completing the technical platform): A secure technical environment for online data analysis will be developed based on user demand.
- **Module 8** (user support and knowledge advancement): NEAR is ahead of schedule, as the implementation of findings began earlier than planned, already taking place in 2023 and 2024 (see: "Construction, development, and operation of the infrastructure, Modules 7 and 8").

2. Construction, development, and operation of the infrastructure

To achieve NEAR's scientific objectives, each module plays a crucial role, both individually and in collaboration, in advancing research on the social, biomedical, and psychological aspects of aging and health.

Module 1 ensures NEAR's efficient organization and daily operations, forming the foundation for fulfilling its scientific missions.

Module 2 focuses on developing and maintaining a secure and efficient technical platform that upholds data quality, security, and accessibility, enabling seamless data identification, management, and analysis.
Module 3 establishes the technical foundation of NEAR by assembling database documentation and metadata. This ensures transparency and facilitates efficient data retrieval across multiple databases.
Modules 4 and 9 are closely interconnected and crucial for NEAR's scientific pursuits. Module 4 harmonizes data across NEAR cohorts, a key step in conducting meaningful analyses and ensuring reliable conclusions. Module 9 provides essential user support, helping researchers navigate NEAR's datasets and technical platforms, optimizing resource utilization and scientific support.
Module 5 increases NEAR's visibility, broadening its user base and facilitating research dissemination. Through strategic communication and outreach activities, NEAR attracts a diverse audience and promotes its unique dataset for advancing scientific knowledge and improving older adults' lives.
Module 6 focuses on expanding and enriching the data collection within participating databases. This has strengthened NEAR's ability to address emerging research topics related to aging biology, clinical complexity, and social and physical conditions. In recent years, additional biological analyses of previously collected serum samples, as well as 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 new databases like ULSAM and HAI. These additions broaden NEAR's investigative purview, particularly concerning metabolic risk factors and cardiovascular health in older men and interventions and promotion for healthy aging. 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 2024 through NEAR findings. In detail, clinical health charts for older adults were validated through a NEAR project, which can be used in primary care.
Module 9 is key also in advancing NEAR's research by developing innovative survey techniques for older populations, smartphone applications for data enrichment, and accelerometer-based physical activity and sleep patterns assessments. 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/or development of equipment if the grant covers this*.
In the spring of 2024, NEAR signed an updated service agreement with Maelstrom Research, establishing the foundation for an interactive e-codebook and harmonization process.

– *Describe how new equipment has been made available and utilized:*
The NEAR platform is continuously updated to maintain optimal functionality and user experience, ensuring accessibility and efficiency for its research community.

– *Describe method development and other development work that has taken place during the reported 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 for individuals aged 72 years and older continued (wave 8). Additionally, in SNAC-K, SNAC-S, and SNAC-B, examinations of a new cohort of 60-year-olds were continued as part of wave 8. In SNAC-S follow-up examinations for individuals aged 78 and older commenced as part of wave 9. SNAC-K also expanded its database with updated linkages to patient, pharmaceutical, and death registers.
- The Gothenburg H70 Birth Cohort Studies: The baseline examination of 70-year-olds born in 1954 was finalized in 2024, while follow-up assessments of 80-year-olds born in 1944 started in the fall of 2024.

NEAR expansion
An agreement was reached to expand NEAR with the Principal Investigators (PIs) of ULSAM and HAI at Uppsala University. The finalization of their inclusion in the consortia is planned for 2025.

Method development
NEAR's ongoing efforts to tackle statistical challenges in multi-center studies have resulted in new methods for handling systematically missing data. These efforts have resulted in publications in relevant statistical peer-reviewed journals and the development of user-friendly STATA commands that enable researchers to apply these methods.

3. Collaboration with other infrastructures

1. NEAR hosted its sixth workshop, *High Impact Aging Research – Dialogue Among International Infrastructures*, in Stockholm, with 109 attendees (80 persons onsite and 29 online). This event brought together leading experts of extensive longitudinal and epidemiological studies or infrastructures, including the Canadian Longitudinal Study on Aging (CLSA), Irish Longitudinal Study on Ageing (TILDA), HUNT – Trøndelag Health Study, and Longitudinal Aging Study Amsterdam (LASA). Insights and potential for international collaborations in the field of aging research were shared.
2. NEAR strengthened its collaboration with key national infrastructures by organizing and attending meetings in Umeå and Gothenburg, as well as online meetings. These collaborations involved the following infrastructures: Comparative Research Center Sweden (CORS); Relations, Work and Health across the life-course – A Research Data Infrastructure (REWHARD); Swedish population databases for research (SWEDPOP); Swedish Infrastructure for Medical Population-based Life-course and Environmental Research (SIMPLER); Evaluation Through Follow-up (UGU); and Swedish Twin Registry (STR).
3. NEAR also engaged with the international Interplay of Genes and Environment across Multiple Studies consortium (IGEMS), NordSOUND collaboration (Nordic Studies on Occupational and Traffic Noise in Relation to Disease), Effects of Low-level Air Pollution – a Study in Europe, (ELAPSE), English Longitudinal Study of Aging (ELSA), and Health and Retirement Study (HRS), resulting in joint publications.

4. Data management and need for supporting e-infrastructure

NEAR's data management strategy aligns with the FAIR Guiding Principles for Scientific Data Management and Stewardship. By adhering to these principles, NEAR aims to maximize the impact and value of its data assets, fostering collaboration, innovation, and scientific discovery across diverse disciplines and research communities.

Documentation and e-codebook. In Collaboration with Maelstrom Research, NEAR continuously updates its interactive e-codebook to ensure comprehensive and accessible metadata documentation. In 2024, meta-data documentation for the newly added databases TRYBO was finalized, while work on SWENIS is ongoing. Updates of the NEAR databases and their presentation on the SND Data Organization and Information System (DORIS), launched by the Swedish National Database Service (SND), ensuring comprehensive data description and accessibility, also occurred in 2024.

Data management. An annual workshop and regular meetings brought together 10 Database Managers led by the NEAR Database Manager Coordinator. They addressed overarching database management issues and explored non-response rates across studies and NEAR platform modifications. Decisions about request management, data preparation, and delivery processes related to secure data transfers. In addition, the Operational Group continued to actively assist 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. A MySQL database has been established at ARC through collaboration with the National Academic Infrastructure for Supercomputing in Sweden (NAISS) to support NEAR's evolving needs. The database is now in the maintenance phase, ensuring stability

and efficiency. Ongoing updates to the NEAR platform, powered by the open-source software OBiBA for Epidemiology, ensure robustness and reliability. Regular backups are conducted on the ARC server reinforcing NEAR's commitment to maintaining high standards in data management and infrastructure support for research on aging and health.

CHANGES IN ORGANIZATION

NEAR underwent some organizational changes:

1. The Software Developer Basile Rommes left the Operational Group in 2024. However, the group expanded by including Peiyu Jiang as a Statistician/Database Coordinator (100%), Adrian Carballo Casla (50%), and Tom Bellander (20%) as Project Coordinators. Moreover, one of the Database Managers, Bolin Wu, went on parental leave in July.
2. In 2024, the Swedish Research Council approved the re-allocation of the grant (registration number: 4.3-2021-00178).

STEERING GROUP ACTIVITIES

The Steering Group holds decision-making authority and assumes full responsibilities for key issues, including: 1) reporting to KI's president, the Parties, and the Swedish Research Council (VR); 2) guaranteeing that the infrastructure is developed and operated in line with goals and deliverables expressed in NEAR application and agreement with VR; 3) ensuring adherence with legal requirements (confidentiality and safety regulations); 4) adherence to policy guidelines; and 5) approval of the strategic plan and annual budget.

In 2024, one meeting together with the Internal Leading Group (ILG) was held. Key discussion topics included NEAR's future vision, organizational and future planning, user fees, and the inclusion of new databases.

FINANCIAL OUTCOME

Approximately 80% of the budget received was used as planned. The unutilized amount of around 6 million SEK (20%) can be attributed to specific factors outlined in the table below. In general, unspent funds were primarily caused by delays in data collection and the hiring of an additional statistician. The co-financing has remained as estimated in the proposed budget.

Description	Amount (tSEK)	Actions
NEAR – Central		
Salary costs: Statistician and Data Scientist	2100	The Data Scientist left NEAR in September, and a substitute will be recruited in 2025. Of the two announced positions as statisticians, one was recruited to replace the statistician who went on parental leave. A new position will be opened in 2025.
Linkage with National registries	400	Reallocated for new cohort (DNR: 4.3-2021-00178).
NEAR - Local		
SWEOLD - Delay in the new data collection	2300	Data collection will be started in 2025.
SNAC-S - Delay in the new data collection	1200	Data collection has started and will be finalized in 2025.

COMMENT ON THE KEY NUMBERS

The number of NEAR applications has increased, with 10 applications submitted in 2023 and 13 in 2024. Additionally, the number of NEAR data users has risen from 60 in 2023 to 70 in 2024. On the other hand, the total number of delivered variables was reduced from 34 688 in 2023 to 21 698 in 2024. However, as part of NEAR's ongoing methodological development efforts, two of the 2024 projects were simulation projects, where no variables were required to be delivered. For more

details about 2024 publications and users' sex distribution compared to 2023, see the sections: “Comment on the publication list” and “Equality”.

COMMENT ON THE PUBLICATION LIST

In 2024, NEAR published 16 peer-reviewed articles involving two or more datasets and two PhD theses. The number of publications has been stable compared to 2023 (15 publications), although fewer PhD theses were completed (two in 2024 vs. four in 2023). Scientific productivity at the local level remains impressive, with 85 peer-reviewed articles, 1 book chapter, and 6 PhD or licentiate theses produced in 2024.

EQUALITY

As outlined in the gender equality plan, NEAR employs more women than men (72% vs. 28%), both centrally and locally. NEAR actively recruited more men to the Operational Group in 2024, including two male Project Coordinators. Thus, in 2024 the sex gap slightly decreased among employees at NEAR, with 68% being women and 32% being men. Regarding data request applications, NEAR had more even sex distribution of PIs and co-applicants in 2024 (54% men and 46% women), than in 2023 (57% men and 43% women). Positively, the sex distribution of PIs of published projects also became more even in 2024 than in 2023 (2024: 56% men and 44% women vs. 2023: 40% men and 60% women). For both the onsite participants at the yearly NEAR workshop and the database manager workshop, 60% were women, and 40% were men. Every year, NEAR reviews the sex distribution of personnel and addresses any deviations in upcoming recruitments.

RISK ANALYSIS

Risk analysis for NEAR in 2024 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, succession planning will be the major focus in 2025 to ensure a smooth transition.
Recruitment challenges. NEAR requires highly specialized staff, which can be difficult to recruit or keep in competition with other employees, such as the industry. Actions are underway to address recruitment difficulties effectively.

EDUCATIONAL EFFORTS, OUTREACH, AND USER SUPPORT

In 2024, NEAR made significant strides in training, outreach, and user support:

- The NEAR Operational Group provided guidance and support to users for 18 projects, up from 15 in 2023, reflecting increased demand for user assistance in data requests, delivery, and harmonization.
- NEAR was showcased at various conferences, including the Nordic Congress of Gerontology in Stockholm, the European Public Health Conference in Lisbon, the Alzheimer’s Association International Conference (AAIC) in Philadelphia, the Anti-Ageism Alliance conference in Florence, the Nordic Aging Society annual meeting, the Collaboration in Science conference, and the symposium titled: "Beyond amyloid and tau: the importance of co-pathologies in Alzheimer's disease" at Karolinska Institutet (KI). A poster was also presented twice at the KI core facility lunch at KI Campus to attract more NEAR users.
- For educational and promoting purposes, NEAR and its study results were also presented at Blekinge Tekniska Högskola, Centre for Demographic and Ageing Research (CEDAR) seminar series at Umeå University, the municipal public health days in Nordanstig, and a seminar series on population health data science research at Queen Mary University of London.
- Members of the Operational Group attended a three-day workshop on: “A simulation-based approach to design epidemiological studies”, a multilevel workshop in R, and the Forum for Science Communication conference.
- Two NEAR newsletters were distributed, sharing updates and activities with approximately 570 recipients. NEAR's online visibility has increased, with 1800 homepage visitors between January 1 and December 31, 2024, and around 4000 views on X during 2024, reflecting growing interest and engagement in NEAR's resources and activities. Moreover, a NEAR LinkedIn account was created in the fall of 2024 and has already gained 152 connections.