Information about the grant
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Period report refers to: 2017-01-01 - 2018-12-31

Scientific report registered and submitted by:
The programme’s research activities

Describe the programme’s research activities until now. This also includes:

- national research exchange
- international research exchange
- dissemination of knowledge (which also includes dissemination of knowledge outside the scientific community)
- collaboration with stakeholders outside the scientific community in planning process and/or through the programme
- aim of collaboration (for example contribute to scientific result, contribute to societal needs and utilisation)

Comment on how the programme has followed the plans regarding:

- Costs (yes/no)
- Feasibility (yes/no)
- Any discrepancy (please describe if the programme, in any aspects, does not follow the plan)

The programme’s research activities

Section I

With the overall aim to generate new knowledge furthering the understanding of user involvement in research on ageing and health, collaboration with non-academic parties is integrated in all facets of the program and a driving force for our research and knowledge translation (KT) efforts. The UserAge program has been initiated and is progressing according to plan. The four-node structure is firmly established with a clear distribution of responsibilities and tasks. As outlined in the program proposal, centring around the development of research questions as a joint endeavour engaging researchers and users, UserAge is organised in three modules: Empirical Research, Capacity-building and Modelling (see figure). Each consists of several projects/activities and is coordinated by a senior researcher. As summarized below, the overall program is proceeding according to plan with only minor deviations:

Empirical Research Module

This comprehensive module includes four PhD student projects (one at each node), the Panel Study (IV) and the empirical part of a cross-cutting project (V) that all are up and running. The fourth PhD project was not part of the original proposal, but was added at LU in Aug 2019, with funding from the Ribbingska Foundation in Lund.

- In the PhD project at Gothenburg University (GU), ethics approval has been received for all studies of the project. Data collection is complete and analyses underway for a grounded theory study with frail older people on their participation in research. Presentations were prepared for Forte Talks and International Association of Gerontology and Geriatrics European Region Congress (IAGG-ER) 2019. Collaboration with community stakeholders has been initiated, which has led to new arenas for further qualitative studies applying PhotoVoice with frail older people and focus groups with healthcare staff.
- The PhD project at Linnaeus University (LNU) focuses on research in partnership with informal carers. Following ethical approval, the first qualitative study about informal carers’ views and experiences of being involved in research and development work started. Data collection and analysis is complete, and a draft manuscript is written. Preliminary finding were presented at several events including a meeting with the Swedish Minister for Children, Older People and Gender Equality about a national carer strategy. Final results were prepared for IAGG-ER 2019).
- The PhD project at Kristianstad University (KU) deals with health care workers’ experiences of collaborating with researchers. A first study related to preventive home visits is under review, and prepared for presentations at Forte Talks and IAGG-ER (2019).
- Attending to the phenomenon of user involvement in research, the empirical research underlying the new PhD project at Lund University (LU) concerns ageing and housing, focusing on the involvement of public housing employees as well as senior citizens’ involvement in research. A first study is in progress, reporting on critical aspects of decision-making regarding accessibility issues in the context of a research circle involving different categories of users. First steps of a second study planned to report on the experiences and lessons learned from
the development of user involvement in the context of the Centre for Ageing and Supportive Environments (CASE) have been taken.

- The survey for the Panel Study has been developed in collaboration with senior citizens in a user forum co-led by a researcher and the Chair of our User Board. The survey has versions for senior citizens, informal carers, professionals, and researchers. To implement the data collection a procurement was completed and awarded to Kantar Sifo.
- The Cross-cutting Project on Methodology, Research Impact and Theory is in the planning phase, and a postdoc was recruited to start more intensive work in early 2019.

Capacity-building Module

- The Think Tank is well established and has met 8 times and led a workshop as part of the second annual UserAge retreat (May 2018). After internal follow-up during spring 2019, the 12 Think Tank members were asked to actively commit for continued engagement in UserAge, resulting in the formation of a smaller group of 9 people.
- The Online Seminar Series is an addition to the program, which is open to all researchers in UserAge and members of our User Board. Four seminars have been held to discuss PhD projects and the Panel Study.
- An addition initiated by the four PhD students is PhD Student Meetings, arranged by them according to their needs and preferences (not including supervisors/senior researchers unless invited for specific matters). They had two meetings in 2018.
- Planning has started for the National Panel Database and Methodological Platform.

Modelling Module

- Work on the Model for Knowledge Translation (KT) is underway, involving co-workers from all four nodes. A short popularised Swedish version of the UserAge program to enhance communication with users is completed. PowerPoint presentations in English, Swedish and popularized Swedish are regularly updated as the program progresses. Program co-workers are often invited as presenters at public events and appear frequently in local and national media. A review of the four UserAge nodes based on the “KT for Ageing and Health” model (WHO, 2012) was carried out concerning their overall approach to KT. The review included text documents, on-line texts and interviews with eight representatives from the four nodes.
- Strategies for the Demonstration of Research Impact were discussed at the first UserAge retreat (Oct 2017). A first case study on research impact was presented at the Nordic Congress of Gerontology (NKG) in Oslo, 2018.
- Initiating work towards the development of the Theoretical Model, involving researchers, users and Think Tank members we have refined the UserAge terminology and concepts, which is an important step towards theory development. For example, while we used the term “user participation” in the original proposal, following international developments we are now using “user involvement”. We have made an explicit distinction between “knowledge users” and “service users”; UserAge is concentrated to different categories of knowledge users. Planning for activities to develop the theoretical model includes the recruitment of the aforementioned postdoc. This planning included consultation with the Think Tank.

Coordination and Integration

- Convened by the PI, the Steering Group includes one senior researcher from each node, the Chair of the User Board and the Program Coordinator as an adjunct member, and meets regularly (two meetings per semester).
- The External Advisory Committee (EAC) is established, chaired by professor J. Phillips, Stirling University, Scotland. Guided by a Terms of Reference document ratified by the Steering Group, the EAC met and provided feedback on the program as part of the second UserAge retreat (May 2018). The EAC members concluded that they appreciated the effort, commitment, management, team working and support within the program. The main content of their first report included positive feedback on the early recruitment of PhD students and establishment of their respective projects, as well as constructive criticism regarding less progress of the Modelling Module, lack of a detailed time plan with milestones and deliverables, and an insufficient integration progress on the program level.
An addition beyond what was planned in the original proposal is the **User Board**, chaired by S. Ålund (representing PRO; a national senior citizens’ organisation). Regulated by a formal description of responsibilities and tasks, their commission is to give active user input to CASE at LU, with a concentration to UserAge. Visiting and providing feedback to each node with special attention to the PhD student projects, the User Board had three documented meetings during 2018, and contributed as co-researchers in a user forum for the development of the Panel Study.

The integration across nodes has been very successful. Each PhD student has a team of supervisors representing at least two of the nodes. One researcher is currently working across three of the nodes, while another is working at two of them.

**Costs and Feasibility**

As we received 75% of the funding applied for, it was necessary to reduce some of the activities in the original plan. The costs and feasibility for the remaining activities are proceeding according to plan. We have maintained our ambitions to have three PhD students with additional funding from other sources, and we even added a fourth PhD student. Three of the PhD students are affiliated with the Swedish National Graduate School for Competitive Science on Ageing and Health (SWEAH), which provides funding and activities to support their learning processes.

The major change from the original proposal plan is the exclusion of the cross-national ambitions with our co-applicants from Italy and the United Kingdom now functioning as international advisors rather than empirical research partners. In the Panel Study, we have reduced our ambition from three successive national survey data collections to two. To reduce the costs further, we subcontracted the data collection to Kantar Sifo rather than hiring additional staff.

Contrasting to these necessary reductions, a junior researcher at GU received SEK 4.4 million from FORTE for a project on user participation in research about and with frail older people (2018-00904). This project is boosting the corresponding project in the Empirical Module. It also add an international facet, which includes an interview study in Australia, targeting older people with migration background and their view of ageing and user involvement. In addition, several of the projects in UserAge make use of data collected in projects funded by other sources (e.g., Formas 2017-01508; Forte 2013-2300; Forte 2015-00043; Forte 2018-01793).

**Plans for further activities within the programme**

Describe the plans for forthcoming activities within the programme. This also include present research tasks and plans for recruitment.

**The programmes forthcoming activities**

**Section II**

The work in each module will continue and accelerate as planned (some activities occurred already in 2019 but are listed here in line with the specified reporting period):

**Empirical Research Module**

- In the **PhD project at GU**, data analyses are ongoing for the first study; a manuscript will be submitted during fall 2019. The study was discussed with the User Board with regard to data analysis and KT, and preliminary results were presented at Forte Talks and IAGG-ER (spring 2019). Ongoing data collection for one focus group study with researchers and another with health care staff will be completed in Oct 2019). These data will be analysed and manuscripts written for submission during 2020. Half time seminar is planned for Dec 2019 with the final defence in Dec 2021.
- A manuscript from the first study in the **PhD project at LNU** was submitted in May 2019, and results were presented at IAGG-ER (May 2019). Making use of data from the Panel Study, the second study is quantitative and aims to describe the views, awareness and understanding of
research involvement among informal carers in Sweden. Literature review and manuscript preparation are ongoing. Data analysis should begin by Oct, and a manuscript will be drafted by Dec 2019. Half time seminar will be in early 2020 with final defence in Feb 2022.

- The first paper from the PhD project at KU was submitted spring 2019. A study visit to Ithaca, NY, USA, was taken in Apr 2019 to learn methods that will be implemented in study II. Results from paper I were presented at Forte Talks and IAGG-ER, spring 2019. The PhD student received funding from SWEAH to visit the Centre for Person-centred Practice Research, Queen Margaret University, Scotland (Sep 2019), where user involvement and knowledge exchange are well integrated at the centre, as well as at a national level. Using Group Concept Mapping to capture researchers’ perspectives on user involvement and participation of professionals, the data collection for study II has been conducted (spring 2019). Data analysis will be completed in early fall and the manuscript will be submitted by end of 2019. Data collection for study III will begin in Aug 2019, followed by data analysis and manuscript preparation and submission during spring 2020. Half time seminar will be in fall 2019 with final defence in Oct 2021.

- The PhD project at LU will produce a manuscript on critical aspects of decision-making regarding accessibility issues in multi-family housing to be submitted fall 2019. The manuscript reporting on the development of user involvement at CASE will be ready for submission early 2020. Study III will make use of Panel Study data on senior citizens’ attitudes and experiences of user involvement in research. Making use of data from a mass experiment (a citizen science method), study IV will investigate the capacity of senior citizens to act as co-researchers in research on ageing and housing. Half time seminar is planned for Aug 2020 with final defence in fall 2022.

- During spring of 2019, the survey for the Panel Study was pilot tested with four groups: seniors aged 60+, informal carers, professionals and researchers. The recruitment and data collection will be completed by Oct 2019. A protocol paper will be submitted for publication in early fall 2019, followed by a manuscript describing the development of the Panel Study in the user forum. Several additional manuscripts are planned. A follow-up survey will be conducted in 2021, which may include additional groups of users.

Capacity-building Module

- Following the development of UserAge and adjusting their activities to the needs and expectations of the researchers and users engaged in the program, the Think Tank will meet 4-6 times per year. A concrete goal is to produce an anthology (in Swedish), presenting different perspectives on the phenomenon of participation. This work will be initiated during a 1-day retreat in Sep 2019 and finalised during 2021. The Think Tank will be engaged in the aforementioned Delphi study.

- The first Online Seminar of 2019 was in Apr and focused on the Model for KT. Three additional seminars are scheduled in 2019. We plan for 4-5 seminars per year for the remainder of the program.

- Following the completion of the Panel study baseline survey, the National Panel Database will be established. We will continue to build on this as follow-up surveys are completed.

- From fall 2019 and progressing during 2020-2022, the Methodological Platform will be established. One researcher will lead this work, which as a concrete goal will produce a book summarising reliable, valid and trustworthy methodologies for research with and about user participation as developed and tested within UserAge. This book will be published in 2022.

- Courses for Users and Researchers will be implemented during 2021-2022.

Modelling Module

- The plan for the Cross-cutting Project on Methodology, Research Impact and Theory (representing integration of the Empirical and Modelling Modules, see Figure) will be finalised early fall 2019. In a first study building on a previous report on an analysis of applicants’ descriptions and review panels’ assessments (commissioned by Forte) we will study how researchers operationalise their collaboration plans as described in a research proposals accepted during 2016. This manuscript will be submitted late spring 2020. In parallel, the postdoc recruited for this project will study the evolving integration of the projects and activities of the program. These results will feed into a Delphi study led by two of the senior
researchers at LU, involving all co-workers of UserAge, the members of the Think Tank as well as external experts. The overall goal of the Delphi study is to establish terminology, methodology and theory for user involvement in research on ageing and health. Specific research questions will be defined during Sep 2019-Feb 2020, followed by the implementation of the Delphi study during Mar-Dec 2020 and subsequent reporting.

- In the KT project, a preliminary synthesis of findings was presented and discussed in a UserAge web seminar in Apr 2019. Researchers and representatives from the User Board took part in the web seminar. Their feedback led to the translation of review questions to target users. Two additional interviews were carried out with UserBoard representatives. The synthesis of the review of the UserAge nodes’ overall approach to KT will be completed during summer 2019. To secure input from a variety of users, a hearing with journalists and the Steering Board of the Swedish Family Care Competence Centre will be carried out in Sep 2019. A draft of the UserAge model for KT will be ready to discuss at our retreat in Oct 2019. It is important to reach consensus on the emerging model so that it forms an integral part of the other UserAge projects and endeavours and is acknowledged by all program partners. A concrete KT activity will take place as the “CASE Day” at LU will be arranged by the User Board (Nov 7, 2019), with research on user involvement as the theme. The researchers continuously engage in public events, including testing out novel modes of KT, e.g. stand-up comedy. Striving to learn from/reach out to public audiences/researchers in related fields, we participate in activities outside UserAge. For example, one researcher participated in the World Parkinson Congress, Japan. This congress has a program format similar to ordinary scientific events, but 75% of the delegates were people with Parkinson’s disease (PD) and family members. In Aug 2019 a delegation from Japan with medical professionals and people with PD visited LU to learn from our research.

- With input from one of our international co-applicants and the Chair of the EAC, during 2021-2022 activities to establish strategies for the Demonstration of Research Impact will be implemented.

- Following the Delphi study, from fall 2020 senior researchers representing different disciplines will lead the work to develop and subsequently present the Theoretical Model on user participation in research on ageing and health. This process will involve all co-workers of the program as well as representatives for different categories of users and result in at least one original publication ready for submission in late 2022.

**Coordination and Integration**

Integration across the program has a very high priority and will be monitored by the program coordinator and the Steering Group. Whenever needed, actions will be taken to strengthen and progress such activities.

- The PI and the Program Coordinator will continuously monitor program progress against the plans in the proposal and the current time plan and list of milestones and deliverables. In addition, they will keep up the communication with Forte, including participation in relevant events organised nationally.

- The Steering Group will continue with two video conference meetings per semester, and one full day meeting each year for more detailed planning.

- We will have an External Advisory Committee (EAC) during the entire program period, with a (partly) renewed constellation for years 4-6. The EAC will meet with the Steering Group and key members (including users) of the program in Nov 2019. Additional meetings will be held annually. Additional input from the EAC will be solicited as needed.

- The User Board met two times during spring 2019; they will meet at least 3-4 times annually.

- Taking turns among the nodes, we will continue to organise annual retreats based on the specific needs of the program. All co-workers in the program as well as User Board representatives will be invited, and when feasible and considered efficient also the EAC. On the day before the 2019 retreat, there will be a PhD student meeting to discuss different concepts used in the different PhD study contexts related to user involvement. The aim of the meeting is to discuss similarities and differences in the PhD project’s findings so far.

**Publications**
Describe the research group’s publications. Specify the publications under two different headlines: Published results and Ongoing and planned publications.

Publications

Published results

Original publications


*Malm, C., Andersson, S., Jönson, H., Magnusson, L., & Hanson, E. Moving beyond the first response phenomenon- exploring carers’ views and experiences of being involved in research and development work. International Journal of Sociology and Social Policy, in press.*

Popular science

Äldre I Centrum, nr 3, 2018: Han samarbetar med forskningen. Author: Lena Fieber.

Äldre I Centrum, nr 2, 2018: Nka bjöd in UserAge till Kalmar. Author: Erik Skogh (UserAge communications officer).

FysioScience, nr 5, 2019: Viktigt att involvera professionen i forskningsarbetet. Author: Anna Horn.

Conference contributions

*International Association of Gerontology and Geriatrics European Region Congress 2019 (IAGG-ER), 23-25 May 2019, Gothenburg, Sweden:*

- Berge, I., Barenfeld, E., Dahlin-Ivanoff, S., Haak, M., & Lood, Q. Frail older people's voices on their participation in research.
- Hanson, E., & Magnusson, L. Quality of care from a carer perspective.
- Iwarsson, S., Berge, I., Etzerodt Laustsen, C., Malm, C., Ålund, S., & Jonsson, O. Understanding user participation in research on ageing and health – experiences and emerging findings from the UserAge program.
- Jonsson, O., Ålund, S., Kylén, M., Frögren, J., Slaug, B., Iwarsson, S., Schmidt, S. Consulting senior citizens in a user forum: an early construction phase of a panel study questionnaire on user participation in research on ageing and health.
- Laustsen, C.E., Petersson, P., Westergren, A., & Haak M. Health professionals’ experiences of being involved in a research project – a case study.
- Malm, C., Hanson, E., & Andersson, S. Carers’ views and experiences of the co-creation of a national carer strategy.
- Petersson, P., Westergren, A., Haak, M., & Edberg, A-K. Developing a model that support preventive home visit for seniors – a collaborative development and research project.

**Forte talks, 26-27 March 2019, Stockholm, Sweden:**
- Berge, I. Frail older people’s voices on their participation in research. Poster P6.
- Laustsen, C.E., Petersson, P., & Westergren, A. Involvement of professionals in research and development projects.
- Lood, Q. Partnering with older people in research: making their voices heard. Poster P17.

**24th Nordic Congress of Gerontology, 2-4 May 2018, Oslo, Norway:**
- Hanson, E. Understanding user participation in research on ageing and health, Symposium presentation, User participation, collaboration, methodological experiences and research impact in research on ageing and health.
- Iwarsson, S. A research impact case study of the Housing Enabler instrument.
- Iwarsson, S., & Hanson, E. User participation, collaboration, methodological experiences and research impact in research on ageing and health.
- Iwarsson, S., Hanson, E.J., Löfqvist, C., Jonsson, O., Haak, M. User participation, collaboration, methodology and research impact in research on ageing and health.

**Nasjonal konferanse om brukermedvirkning i forskning, 16-17 October 2017, Lillehammer, Norway:**
- Jonsson, O., Dahlin-Ivanoff, S., Hanson, E., Edberg, A-K. & Iwarsson, S. on behalf of the UserAge Consortium. UserAge: A research programme on user participation in research on ageing and health.

**21st World Congress of Gerontology and Geriatrics, 23-27 July 2017, San Francisco, USA:**
- Hanson, E.J., Edberg, A., Dahlin Ivanoff, S., & Iwarsson, S. Understanding user participation in research: methodological considerations.
- Iwarsson, S. Knowledge translation based on research on home, health and disability along the process of aging. Keynote abstract.
- Iwarsson, S., & Hanson, E.J. User participation in aging and health research – bridging science, policy, and practice.
- Iwarsson, S., Jonsson, O., Dahlin Ivanoff, S., Edberg, A-K., & Hansson, E. Understanding user participation in research: conceptual and theoretical underpinnings.
- Jonsson, O., Slaug, B., Haak, M., Tomsone, S., Schmidt, S., & Iwarsson, S. Appropriateness of a housing accessibility app: findings from the European innovAge project.

**AT Forum, 10-11 May 2017, Malmö, Sweden:**
- Iwarsson, S., Jonsson, O., Haak, M., Tomsone, S., Schmidt, S., Mårtensson, K., & Slaug, B. Bostadsappen: ett nytt verktyg för bättre tillgänglighet i boendet.