

UserAge

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CASE

CENTRE FOR AGEING AND
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Understanding User Participation in Research on Ageing and Health

UserAge

A 6-year inter- and transdisciplinary research program implemented as

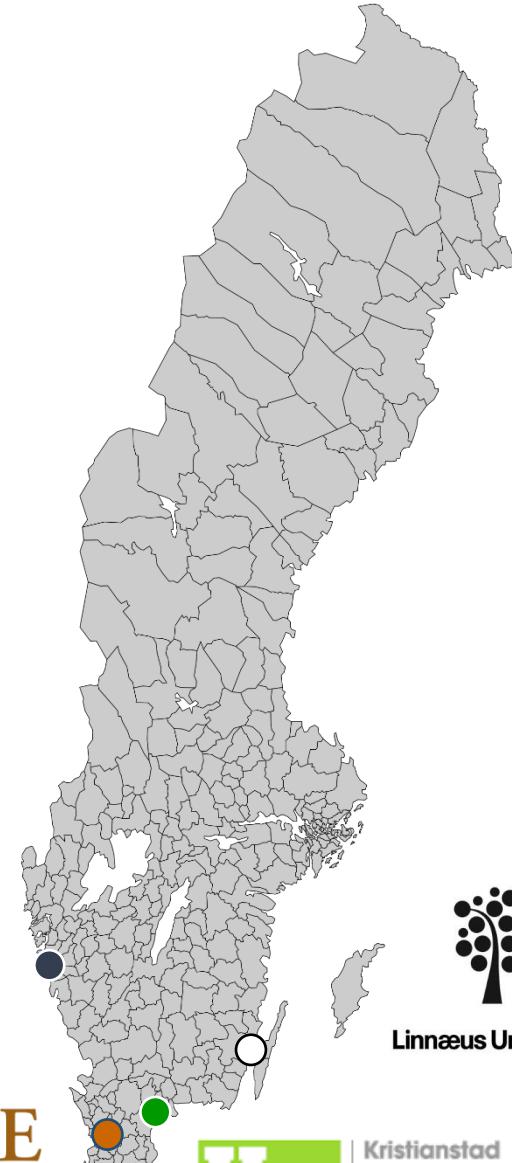
- a four-node endeavor
- with international collaboration
- coordinated by the Centre for Ageing and Supportive Environments (CASE), Lund University



Swedish Research Council for
Health, Working Life and Welfare



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UserAge partners

Lund University

- Susanne Iwarsson (Principal Investigator)
- Steven Schmidt (Programme Coordinator)
- Maria Haak (Kristianstad and Gothenburg as well)
- Oskar Jonsson (Linnaeus as well)
- Håkan Jönson
- Björn Slaug
- Maya Kylén
- Sara Hultqvist (Postdoc)
- Joakim Frögren (PhD student, funded other sources)
- Erik Skogh/Agata Garpenlind (Communications Officers)
- Stig Ålund (Chair, CASE & UserAge User Board)

International collaborators (co-applicants)

- Giovanni Lamura, INRCA, Italy
- James Goodwin, AgeUK, United Kingdom

Kristianstad University

- Albert Westergren (Partner responsibility)
- Anna-Karin Edberg
- Pia Petersson
- Christine Etzerodt Laustsen (PhD student)

University of Gothenburg

- Synneve Dahlin Ivanoff (Partner responsibility)
- Qarin Lood
- Emmelie Barenfeld
- Isak Berge (PhD student)

Linnæus University

- Elizabeth Hanson (Partner responsibility)
- Lennart Magnusson
- Stefan Andersson
- Camilla Malm (PhD student)

Understanding User Participation in Research on Ageing and Health

- Addressing active and healthy ageing and the challenges in welfare systems demands new solutions
- User participation in research is being advocated for as a way to improve such services



Medborgare

Partners

Serviceanvändare

Experter

Kunder

Intressenter

Allmänheten



TYCK! | SPF SENIORERNA I BJÄRNUM

Foto: Mostphotos

Kalla oss inte brukare!

Ordet brukare är en styggelse. Varför inte använda vårdtagare, patient eller vårdbehövande i stället? föreslår SPF Seniorerna Bjärnum genom styrelsen.

Produktanvändare

Konsumenter

Kunskapsanvändare

Seniorer

Klienter

Medforskare

Representanter

Samverkansparter

Patienter

Behovsägare

Who Are the Users?

A broad definition of “knowledge users” including all parties interested in and/or beneficiaries of research on ageing and health:

- senior citizens in the general ageing population
- vulnerable people with specific characteristics, needs and preferences
- informal carers/family carers
- health care, social services professionals
- industry professionals
- public agency officials and policy-makers
- interest organization representatives

*Challenging to
communicate clearly!*

Developed involving users

Senior citizen (NGO outside Sweden):
"For the researchers, user involvement, knowledge translation and research impact are intellectual issues, but for older people these are emotional experiences."

Senior citizens (several individuals):
"Scientific jargon is a problem, both spoken and written. There is a risk putting older people off."



Politician, regional level:
"I think that the statement that users must be able to represent more than themselves is unrealistic. Can that really be expected from, for example, frail older people?"

Examples of input from user representatives while developing the research program proposal

Ultimate Goals

- Maximize the impact of user participation
- Enhance the execution of high-quality research
- Increase the knowledge about what difference user participation can make
- Evaluate the extent to which research about and with user participation makes an impact on practices and outcomes

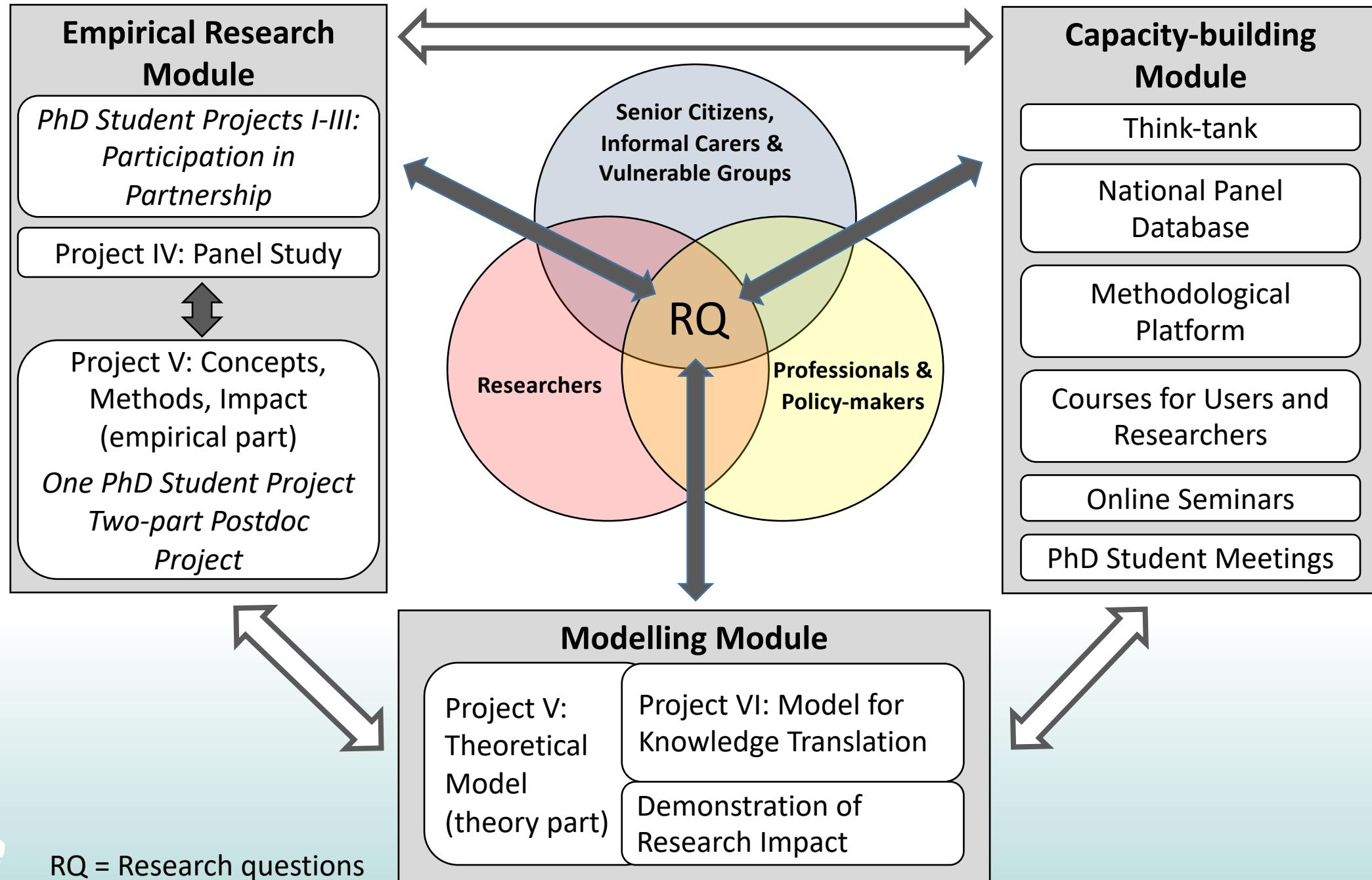
Forms of participation	Characteristics	You get to	Examples of methods
Information	One way communication	Know	Newspapers Webb General meetings
Consultation	Gathering opinions	Express opinions	Survey Focus groups Citizen panel
Dialogue	Exchanging ideas	Discuss	Open Space
Cooperation	Planning and doing	Do things	Work group Future workshop
Co-decision making	Deciding together	Decide	Participatory budgeting

Huddinge spectrum of participation (Lindholm & Moritz, 2007), with permission from the originators.

Overall Research Questions (RQ)

- What are the significant meaningfulness, challenges and opportunities of user participation at individual, group, and societal levels and in a cross-national perspective?
- What are the awareness of, understanding of and attitudes to user participation among different categories of users, and researchers – in Sweden and in cross-national comparisons?
- What are the optimal ways to communicate and translate research findings involving different categories of users?

Three Programme Modules



**Cross-cutting
Projects
Builds Upon
Previous/
Ongoing
Research
with User
Participation**

Empirical Research Module

PhD Student Projects I-III: Participation in Partnership

Project I: Making the Voices of Frail Older Heard

Project II: Informal Carers (incl. cross-national part)

Project III: Professionals and Policy-makers

Project IV: Panel Study



Project V: Concepts, Methods, Impact (empirical part)

PhD Student Project: User Participation in Research
(a. housing sector; b. within CASE and UserAge)

Postdoc Project: User Participation in Research
(a. Forte-funded projects; b. within UserAge)

Cross-cutting Activities on Research about User Participation

Capacity-building Module

Think-tank on Participation

National Panel Database

Methodological Platform

Courses for Users and Future Ageing and Health Researchers

Online Seminars

PhD Student Meetings

Modelling Module

Project V (theory part):
Theoretical Model for
Ageing and Health
Research With and
About User Involvement

Project VI: Model for
Knowledge Translation
Demonstration of
Research Impact

Programme Management Structure

- Steering Committee, chaired by Susanne Iwarsson
- CASE & UserAge User Board, chaired by Stig Ålund
- External Advisory Committee, chaired by Judith Phillips
- Programme Coordination and Administration, Steven Schmidt and Ingrid Hilborn

Thanks For Your Attention!



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