

Aging & Later Life Program Description

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1. Introduction

An aging population affects everyone: young people have to take care of older generations, while medical and healthcare services have to respond to new societal and scientific developments. The *Aging & Later Life* research program aims to help people in the Netherlands grow old and be old in the best possible way. Launched in 2015/2016, *Aging & Later Life* conducts its research mainly within the University of Amsterdam Academic Medical Centre (AMC/UvA) and at the VU University Medical Centre Amsterdam (VUmc/VU), and in Amsterdam and its surrounding areas.



Figure 1 - The matrix structure of the *Aging & Later Life* research program. The vertical pillars represent the three stages of the aging process, from 'Aging' to 'The Last Years of Life'. Running through these stages like a red thread are three themes that form the basis of the research program. Each theme is examined in the context of each stage of the aging process.

2. Vision

There is no such thing as the typical older person. Older people are not a homogeneous cultural group, and the process of aging affects different people in different ways. But what many older people do have in common is a desire to grow old gracefully and live well, to enjoy their twilight years and then die with dignity. At *Aging & Later Life* we want to help all older people to achieve this, so we think it is important that nobody is overlooked.

Aging & Later Life is a multidisciplinary, cross-departmental research program. We focus specifically on the concepts of *resilience*, *quality of life*, and *personalised care* during the three stages of the aging process: growing old, being old, and the last years of life. It is important to note that these concepts can mean different things in each phase of the aging process.

Currently, aging research focusses either on the idea of “loss” — in which vulnerability is defined negatively in terms of frailty — or on “healthy aging”, which, by emphasising success, leaves little

room for older people who can't achieve this ideal. By contrast, the idea of *resilience* — "the ability to bounce back in the face of adversity" — focusses on older people's capacity for responding to specific age-related tasks and transitions. As such, *resilience* recognizes older people's innate strength, without establishing an absence of problems as the norm for a good old age. By using the concept of *resilience*, we aim to provide a more realistic, more inclusive alternative that will help us better understand, investigate and address vulnerability.

For many older people, full physical health is often unachievable. But this doesn't necessarily mean that they can't experience a good *quality of life*. A "good" life is determined by more than just physical health — it also depends on the extent to which people can continue to get value and meaning out of life after suffering a health setback. At *Aging & Later Life*, we therefore investigate how individual and structural factors can affect the *quality of life* of older people, and people in the final years of life. We think it is important to recognize and respect the personal meaning people assign to the concept of *quality of life*.

As well as older people's differing values and preferences, another factor that contributes to the growing variety of clinical profiles is an increase in multi-morbidity. There is a growing awareness of group differences in health effects or treatment results, and of the influential factors at play. We therefore need to know more about *personalised care* in healthcare. Amsterdam, a model of our increasingly diverse society where over 180 nationalities are represented, needs this more than anywhere else in the Netherlands. We want our research to help provide deeper insights into what kind of care works for whom, and when.

We want to avoid our research results being overlooked. That is why both scientific quality and social impact are central to us. Our interdisciplinary approach and active exchange with other faculties, field partners and educational institutions are essential to achieving the impact we want. We strive to make research questions relevant and urgent for both researchers and stakeholders. Older people themselves are also important here: their perspective is essential to doing individually-relevant work. Our goal is to listen to the full spectrum of voices, because after all, there is no such thing as the typical older person.

3. Goal

Our job is to improve our understanding of the complex process of aging, being old, and experiencing the last years of life. Our goal is to promote the visibility of and the discussion around the increase in physical, mental and social vulnerability that occurs as people get older. Our ambition is to produce high quality research and to achieve maximum impact on social policy and care.

The more we increase our knowledge around aging and being old, the more questions arise, and the less effective traditional approaches appear to be. There is a widely-felt need for new concepts and clinical measures that can provide a basis for innovation and evaluation. In order to have a conversation about what constitutes a good life — and how our research can contribute to it — we must pay attention both to elderly people's experiences, and to the specific needs that arise as people become more vulnerable. We will only be able to make room for developments like these if our research can look beyond the existing dichotomies: healthy/unhealthy, young/old, strong/vulnerable. We will use the knowledge we gain to design and evaluate (preventative)

treatment and care strategies, and work closely with stakeholders to translate these strategies into practice. In this way, we contribute to delivering care that allows people to grow old in a way that suits them, in a society that is properly equipped to support them.

These goals are inextricably linked to questions of social responsibility. *Aging & Later Life* therefore aims to become a multidisciplinary platform that shares the results of its research with clinical practice, and also translates them for the benefit of society. We actively work with partners in research, care, local government, and secondary and vocational education to achieve this.

4. Program content

In order to achieve the above objectives, *Aging & Later Life* focuses on three main themes: *resilience*, *quality of life*, and *personalised care*. The following describes these themes in the context of the three stages of the aging process: 'Aging', 'The Older Person', and 'The Last Years of Life'.

Aging

This addresses the process of *growing old*.

In this theme, researchers from *Aging & Later Life* study the process of aging, and consider the clinical, genetic and social factors that can explain the variances that occur. This phase is not limited to studying older communities, because research aimed at younger communities also contributes to our knowledge about aging, and helps to form a clear picture of the variances within the aging process.

Research into *quality of life* focuses on the question of what the main medical, functional, cognitive, communicative and social pillars of *quality of life* are, and what roles they play in the aging process. Knowledge about *personalised care* goes hand in hand with research into the contribution of genetic, environmental and behavioural factors to the development of chronic diseases, multi-morbidity and loss of function. Because the Netherlands is becoming more and more diverse, especially in cities, we study the ways biological and socio-demographic differences affect the aging process. Finally, we consider the vulnerability of the body as it ages, but emphasize its *resilience*. Why is it that some people still experience a good *quality of life* in spite of their limitations?

Within this theme, we also consider the effects of aging on society, and on healthcare in particular. This includes research into the impact of aging on national laws and regulations, such as changes to the general law on exceptional medical expenses (AWBZ) and the social support act (WMO), or changes to social systems, such as caregiving, informal care networks and family support. Finally, we examine the labour market, for example the consequences of changing the retirement age. An aging population means we must think differently about the architecture and layout of housing, public transport and shopping centres. We must therefore study not only new healthcare policies and innovations, but also urban planning and policy, for which older people's perspective is essential.

We will use the knowledge we gather within this phase to map health risks and develop tailored interventions. This will help us to prevent age-related diseases, develop *personalised care*, and stimulate innovation in the areas of housing, working, and living.

The Older Person

This addresses the state of *being old*.

People are living longer than ever, but in their old age they experience more conditions and limitations, often chronic in nature. *Aging & Later Life* wants to highlight the issues around the increased likelihood of problems in this phase.

Nowadays, elderly people prefer to live independently and to participate in society for as long as possible. But this becomes more difficult the older people get, as their social network thins out, their physical and mental abilities deteriorate, and their need for care rises. This means that elderly people become more vulnerable, whether they are living in their own home or in a nursing home. We investigate the ways in which these increasingly vulnerable older people can continue to live independently at home as much as possible, and how they can retain as much control as possible over their life when independent living is no longer an option. In this respect, it is important to understand the differences in people's care needs and capacity to participate, as well as the way in which elderly people express themselves about their illnesses and limitations. We also want to understand why some older people are so much more vulnerable than others who live in similar circumstances. The concept of *resilience* can provide a useful framework here. Being vulnerable — or indeed resilient — can be applied not just to individuals but also to systems. If an individual's health problems stack up, or if their health is progressively deteriorating, for example in the case of dementia, this puts pressure on the relatives and/or friends who are taking care of them. We therefore also study the health, well-being and quality of life of caregivers within this phase.

The main research themes are prevention, diagnosis and treatment of the somatic and psychosocial problems that commonly occur in old age. These include cognitive dysfunction and falls, functional and sensory impairment, polypharmacy, atypical presentation, and other interacting components. Although most clinical guidelines currently only address single conditions, it is important to note that managing people with multi-morbidity is much more complicated than managing people with a single condition. We are therefore conducting research into the development of adequate and appropriate diagnostic tools that allow us to quantify functioning in specific domains, and to disentangle how co-existing disorders interact. This will help us to create a personalised approach to problems.

The healthcare sector is undergoing major changes due to changing demographic trends. One of its biggest challenges is the shrinking workforce in the healthcare sector. In order to be able to offer high-quality, effective, *personalised care*, we need to look for innovative solutions as a society. To contribute to this, *Aging & Later Life* is investigating the possibilities that technological advances can offer to elder care — for example, the application and added value of e-care, GPS systems and robotics. Change is necessary not only at the content level of healthcare, but also at the systemic level. The pressure on healthcare necessitates a shift from formal to more informal care arrangements. Research into how to initiate and support the participation of older people in the community, as well as into the extent to which social networks can contribute to caregiving, helps society find alternatives that are in line with the current changes in healthcare.

The Last Years of Life

Research within this theme addresses ways of making the *last years of life* as enjoyable as possible, and dying with dignity. Although most people in this phase are elderly, 'the last years of life' and 'the final stage of life' are not by definition synonymous with old age. Consequently, we do not focus exclusively on older people, but also on people who die prematurely.

During the last years of life, *quality of life* and well-being become vitally important. Adequate, timely, *personalised care* that suits the needs and situation of each patient are essential for providing good care. The focus shifts from curative treatment to preventative or palliative treatment, and to the possibilities for optimizing daily well-being, and counteracting or reducing the loss of *quality of life*. This includes, for example, research into pain and pain relief, preventing and treating delirium, treating infections, and appropriate medication, or research into the needs of patients and the people around them towards the end of life, as well as different perspectives on appropriate care.

The existence of different views on what constitutes good care irrevocably raises medical and ethical questions for researchers, as well as for clinicians and other healthcare professionals. These questions are often echoed in social debates, and increasingly appear on the public agenda. Within this theme, we therefore consider the individually-experienced and socially-considered medical-ethical dilemmas that can come into play when caring for people in the final phase of their life. Researchers from *Aging & Later Life* aim to study and question the standards around (the limits of) continuing treatment, self-reliance and vulnerability, and to translate this into treatment options in clinical practice.

Finally, in this phase we investigate ways to organize care effectively and efficiently, for example, by continuing to develop and evaluate geriatric rehabilitation programs, and by thinking of strategies to minimize care transitions, or improve palliative care pathways. We hereby make critical use of the theoretical and conceptual foundations of care interventions, such as research on advance care planning, shared/collaborative decision making, and goal-setting. In line with the *Aging & Later Life* vision, we consider the perspectives of both the care recipient and the caregiver as indispensable components for developing and evaluating an adequate program.

5. Collaboration

Aging & Later Life aims to collaborate closely and actively with practitioners in healthcare, higher education and vocational education. The program is relevant both nationally and internationally and aims to establish partnerships within, for example, European working groups and national research groups and consortia. Relevant local partners include: University Primary Care Practice (UHP VUmc), University Elderly Care Medicine Practice (UPO VUmc), Academic Network General Practice (ANH-VUmc), Consortium for Palliative Care, University Network of Long Term Care Organizations (UNO-VUmc), the Expertise Centre on Palliative Care (EPZ), the Ben Sajat Centre (Long Term Elderly Care), the Amsterdam Centre on Aging (ACA), and several centres of excellence and working groups on specific conditions and issues such as falls, osteoporosis and sensory deficits.

As well as collaborations within the field of research, researchers in the multidisciplinary *Aging & Later Life* program group are also involved in interfaculty partnerships within and between knowledge institutions. This helps us approach 'Aging', 'The Older Person', and 'The Last Years of Life' from different theoretical and methodological perspectives. The researchers have extensive experience in performing experimental studies, qualitative research, mixed methods studies, meta-analyses, and complex multidisciplinary interventions including randomized controlled trials (RCTs), and cohort studies. Large-scale (continuous) cohorts under the supervision of members of the program group include Longitudinal Aging Study Amsterdam (LASA), the RAI database, LTCF Ysis database, the Dutch hunger winter cohort, Prevention of Functional Reduction in Elderly Persons in Primary Health Care (FIT), and NL-SH, which cover the entire range of aging as well as various intra- and extra-mural care environments. Participation in the program by clinical professionals ensures optimal translation into practice.

There is close collaboration between *Aging & Later Life* and other APH research programs. We have a lot in common with the Personalised Medicine program, for example in the case of individualized diagnostic testing and treatment modalities. We work closely with the Methodology program to optimize and improve the data analysis methods of these complex systems, and to develop diagnostic and treatment modalities, such as decision-making systems based on shared decision making. We work with the Mental Health, Social Participation, and Quality of Care programs to optimize prevention, treatment and care strategies that improve the *quality of life*, functioning and participation of elderly people during the aging process. We also work with the Social Participation program to evaluate preventative care and social programs.