

Long-Term Care Partnership (LTCP) Position Paper

Mission statement

The Long-Term Care Partnership, based in the Centre for Social Science and Global Health (SSGH) at the University of Amsterdam (UvA), brings together the expertise of academic researchers, stakeholders and care providers with the aim of carrying out cutting-edge research, training and inspiring young researchers, and developing innovative care initiatives relating to long-term care, and with a specific commitment to linking scientific research to care practice.

Background

Long-term care is a key issue for the 21st century. While the need for care is expanding, health budgets are increasingly under pressure. As a result, the organization of long-term care for the elderly and those with physical, psychiatric and intellectual disabilities and needs is changing. New care arrangements often blur the boundaries between formal and informal care: characteristics of long-term care arrangements that used to coincide (such as home care being provided by the family and paid care being provided by professionals) are unravelling in many European countries (due to the introduction of home care services, privately hired migrant home care providers and cash-for-care schemes).

These changes not only have far reaching consequences for those in need of long-term care, but also for their carers. First, the increasing care burden for informal family carers leads to stress and burnout as a result of trying to combine care with work and domestic responsibilities, and this in turn has deleterious consequences, for example for gender equality due to the fact that most carers are women. Second, informal migrant carers, who are increasingly turned to in order to supplement family care, are exposed to exploitation and as a result their own domestic care responsibilities suffer. And third, formal carers are under increasing pressure to perform caring tasks in limited time and with limited resources under difficult circumstances, they lack autonomy and influence on the way the tasks are carried out, and their work is often insufficiently appreciated. While providing care is generally experienced as meaningful, long-term care provision is also often highly repetitive, unappreciated, and with little chance of improvement in the condition of those they care for. In societies that are focused on progress, innovation and improvement, *maintenance* receives scant attention and value because it is considered self-evident. It is important to understand how changes from formal to informal and from institutional to home care affect care providers and, consequently, the quality and sustainability of care.

Ageing populations are increasingly central to these changes. We live in a rapidly ageing world. By 2030, the number of people aged 65 and older is projected to reach 1 billion (or one in eight of the global population), and to rise by 140% in developing countries (NIH 2007). Longevity brings with it complex chronic conditions that are expensive to manage. So while the burden of care will increase substantially, potential carers will become increasingly scarce due to declining birth rates.

Welfare state reform also has huge implications for citizenship of long-term care recipients and care givers. Legal rights to care are reduced and new obligations to provide care or to 'participate' are introduced. At the same time, new options for

participation also arise, for example as a result of the increased attention to reciprocity. Citizenship has been a predominant ideal in long-term care, but in practice many care recipients do not experience full-fledged citizenship: they lack the conditions and options for full participation in the labour market, education, and social and political spheres. As a result, new practices and ideals of citizenship may be needed, for example focusing less on autonomy and more on reciprocity and interdependence.

These issues are crucial in the context of an ageing population and welfare-state reform in the Netherlands, but also beyond that, in Europe and globally. Welfare-state reform has become a dominant issue across much of the global North while shortage of care resources has always characterised the global South. Moreover, mobility, migration and multi-cultural societies have made questions of care, responsibility and citizenship more complex and more global. So while cheap migrant carers are becoming increasingly important in the long-term care landscape of Northern countries, care migration by ageing Northerners to cheaper Southern countries is clearly on the horizon (for example the *Malaysia My Second Home* initiative). Ageing populations, the increasing prevalence of dementia, shortages of resources for long-term care, increasing mobility, and the wider social implications of these, are problems that go beyond the borders of particular countries and, in the longer term, call for more global solutions.

What is needed is both fundamental research on the key concepts in the debate (such as care, identity, citizenship, reciprocity), how they are being affected by change, and how this impacts on the practice of care, and applied research aimed at improving the practice of long-term care for those who need it in the context of complex and changing societies. This research needs to focus on local and national situations and issues, as well as on international and global processes, enabling an understanding of the wider context of challenges to long-term care as well as the comparison of similar issues across different settings leading to theoretical insights and practical lessons that can be applied elsewhere.

The Long-Term Care Partnership (LTCP)

Aim and objectives

The Long-Term Care Partnership has been established to address these issues. The overall aim of the Partnership is *to promote, and carry out, fundamental and applied research that will lead to better long-term care for the elderly and those with physical, psychiatric and intellectual disabilities, and to improved quality of work for their care providers.*

The specific objectives are:

1. To carry out and promote applied social scientific research on long-term care and to translate the results of this research into improved care practice.
2. To carry out fundamental research aimed at better understanding the sociocultural context of changes in long-term care and the underlying processes relevant to these changes, and to address the important theoretical and ethical issues relating to long-term care.

3. To obtain funding to expand the Partnership's existing programme of research in Netherlands and beyond, integrating it into the UvA's Global Health agenda.
4. To obtain funding to facilitate implementation of results from the Partnership's research programmes.
5. To train and inspire young scholars to carry out research on long-term care.
6. To develop a national and international network of researchers involved in studying issues relating to long-term care.
7. To develop a network of care organisations that are prepared to play an active role in supporting scientific research, translating the results of this research into care practice, and disseminating them to the broader care community.
8. To disseminate the results of research widely through scientific publications, conference presentations, and the media.
9. To contribute to the broader social and political debate on themes that are relevant to long-term care.

Origins, main partners and collaborators

The basis for the LTCP was formed by the confluence of a number of recent collaborative efforts and funding initiatives (not necessarily in order of chronology or importance):

The Gieskes Strijbis Fund, that supports socially relevant research, decided to invest in research on dementia care with the explicit aim of improving care practice. The result was the establishment of a research programme and an endowed chair for Long-term Care and Dementia at the UvA. Anne-Mei The was appointed to the chair in 2012.

This chair is linked to the Centre for Social Science and Global Health (Anita Hardon, Robert Pool), part of the Research Priority Area Global Health at the UvA, which recently received additional funding from the university for a programme of research on *Innovations in Global Health Care*. Through this the UvA has made resources available to facilitate research on care from a global health perspective.

The Ministry of Health, Welfare and Sport (VWS) has made funds available to evaluate *De Werkvloer Centraal*, an initiative set up by Anne-Mei The, aimed at improving long-term care by motivating carers, and thereby enhancing their relationship with the clients.

The UvA Research Programme Group *Dynamics of Citizenship and Culture* (Jan Willem Duyvendak, Evelien Tonkens) has been carrying out important research on care in the Netherlands for many years and is a leading centre of care-related research in Europe.

For some time Cordaan (Eelco Damen, Henk Kouenberg), an Amsterdam-based organisation that provides institutional and home-based care, has been calling for more attention to be devoted to the problems of ageing populations and long-term care in Europe. Cordaan is currently developing new policies on dementia and youth with learning disabilities in the city of Amsterdam.

In 2010 the Research Programme Group *Dynamics of Citizenship and Culture*, together with Cordaan and a number of other organisations, held an international conference in entitled *Does Europe Care?* in which participants from across Europe exchanged knowledge and experiences relating to development in long-term care.

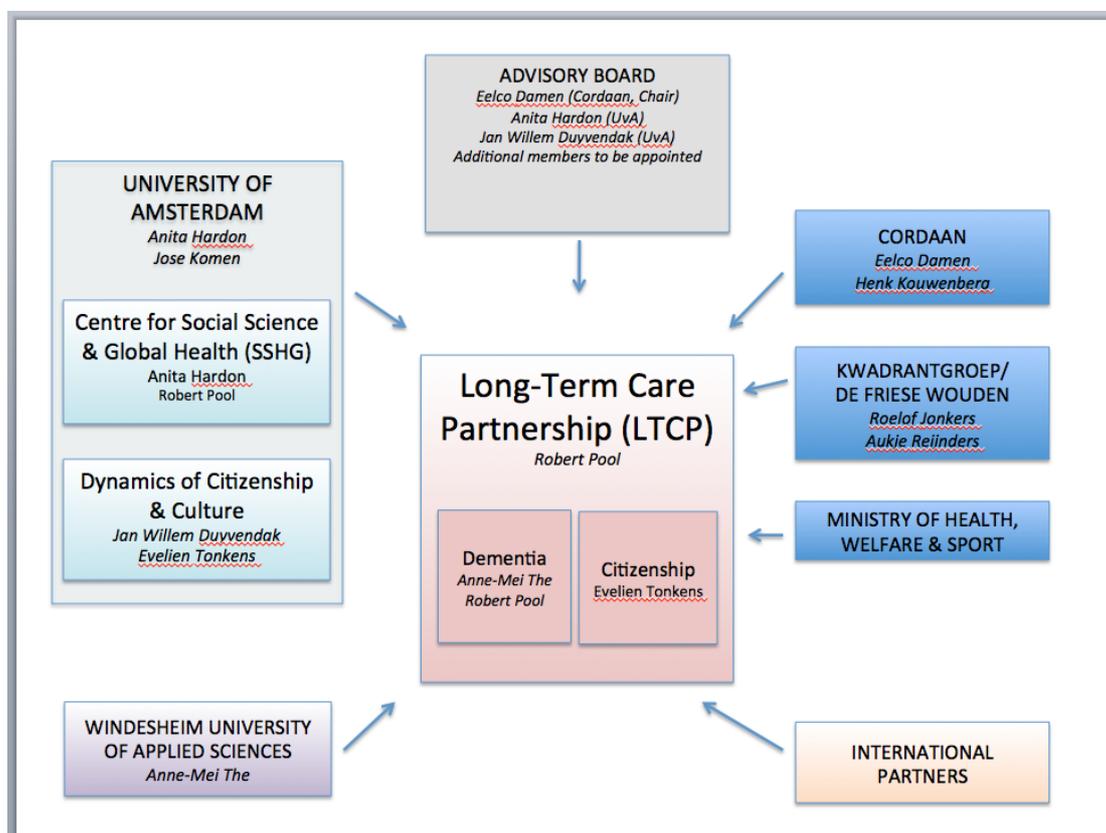
In 2013 Cordaan and the UvA made a collaboration agreement to financially support the chair in *Active Citizenship* (Evelien Tonkens) as well as two PhD projects relating to long-term care.

The Kwadrantgroep/De Friese Wouden (Roelof Jonkers, Aukje Reijnders) a care organisation in the north of the Netherlands, has been at the forefront of integrating care and cure and, in collaboration with Anne-Mei The and Liz Cramer, is developing innovative approaches to care for those with dementia. This was the first care organisation in the Netherlands to use Dementia Care Mapping, an instrument for observing how nursing-home residents with dementia feel and how that relates to the behaviour of the care providers.

Since 2011 Anne-Mei The has led the Lectorate in Palliative Care and Dementia, *The Windesheim University of Applied Sciences*, which is involved in applied research on the different stages of dementia.

Building on these developments, and based on agreement between the UvA and Cordaan, the LTCP thus brings together a number of groups and initiatives relating to long-term care (Fig. 1).

Figure 1. Organisation of the Long-Term care Partnership (and the responsible individuals)

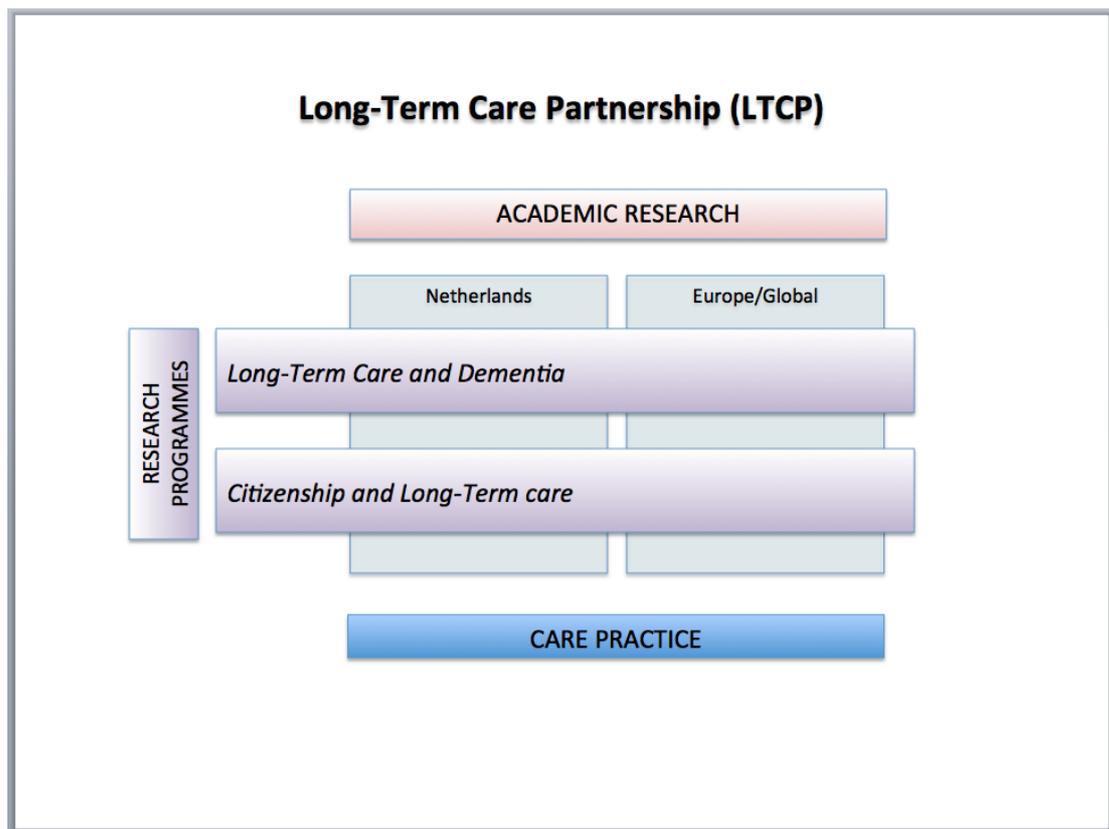


The Research programmes

The LTCP currently consists of two main research programmes, one on citizenship and long-term care and one on long-term care and dementia. In the coming years the LTCP will develop and consolidate these programmes further, and also develop new programmes relating to long-term care. Although these programmes currently focus mainly on the situation in the Netherlands, there are also existing collaborations and research projects in other European countries and beyond that are relevant to the current LTCP programmes.

While the short and medium-term goal (the next 5 years) is to consolidate the current research programmes and the integration of work within the LTCP, the longer-term goal is to increase the number of research programmes and to develop and expand research on long-term care, giving it a more global focus as part of the University of Amsterdam's Research Priority Area Global Health. The overarching aim of the LTCP is to link research to practice through these component programmes (Fig. 2), and it is our view that international research and collaboration, across a wide range of cultures and care settings, will ultimately benefit care practice in the Netherlands.

Figure 2. The Research Programmes



To this end a number of funding initiatives are already under way. For example the *CareQuests* programme, an ambitious proposal for 10-year funding from the Dutch government (NWO) will study how ordinary people care for themselves and each other in daily life, what techniques they use to achieve wellbeing (and what they

understand by wellbeing), and what makes these techniques work for them. Analogous to the reverse engineering of machinery and software, the programme aims to identify and then reverse engineer the everyday life techniques of 'good care', thus enabling care practices that work in one setting to form the basis for innovative practice on other settings.