Memorabel

Summary of the programme document for phase 2 of Dementia Research and Innovation Programme

ZonMw

Summary of the programme document for phase 2 of Dementia Research and Innovation Programme

Memorabel

Memorabel is a research and innovation programme administered by ZonMw as part of the Delta Plan for Dementia. It fulfils one of the three goals of the Plan: research and development for people with dementia. Memorabel also constitutes the national implementation of the EU Joint Programme – Neurodegenerative Disease Research (JPND) initiative. Memorabel, an eight-year research and innovation programme, was launched in 2013 on behalf of the Ministry of Health, Welfare and Sport. Phase 1 runs from 2013 to 2016. This document is a summary of the programme document for Memorabel phase 2, from 2017 to 2020.

Continue on same path with greater focus on use of knowledge

In phase 2 Memorabel will continue on the same path, consolidating the benefits already gained by facilitating the most relevant and best-quality studies, spread across all research themes, but with a greater focus on the use of knowledge. The themes – which are in line with the agendas of Alzheimer Nederland and the JPND initiative – determine the research priorities. Phase 2 will provide an opportunity to use and further develop the benefits and results from phase 1 and from all the scientific research. More directed efforts to foster participation is also high on the agenda for phase 2, along with the expansion and intensification of collaboration with all parties concerned. In phase 2, content will be brought into line with the latest developments and with the update of the JPND Strategic Research Agenda (SRA) which will be published in 2017.
ZonMw selects the best projects on the basis of independent reviews and assessments. For more information on ZonMw procedures and the organisation, visit the website of ZonMw.

Goal

The goal of 'Memorabel' phase 2 is again to gather knowledge that might in the long term help to stem the growth in the number of patients (caring for tomorrow's patients), improve the quality of life of people with dementia, and improve the care and support they receive (caring for today's patients). It will do so by 1. facilitating cutting-edge research that gives us a better understanding of how dementia occurs and how to prevent it, as well as points of action for diagnosis and treatment, and 2. developing and applying effective and workable tools, interventions, care models and innovations designed to improve quality of life and the quality and efficiency of integrated care and support for people with dementia and their informal carers.

The programme document sets out the priorities for the four themes for the period 2017-2020. These themes are:
1. Cause and mechanism of the disease
2. Diagnosis
3. Treatment and prevention
4. Efficient care and support

Revised priorities

The priorities have been defined more clearly, partly on the basis of input from people with dementia and their informal carers. There will for example be a greater focus on longitudinal cohort research. Under the theme of diagnosis, studies of biomarkers are expected to produce the most results over the coming years. Under theme 3, efforts will be brought more in line with the latest insights regarding lifestyle and the experience of people with dementia, and there will be more scope for studies into combinations of interventions to improve care. Theme 4 will focus more on care and support for people with dementia in their own home, multidisciplinary collaboration and the role of informal care. These efforts will have to be compatible with the new care system, in which care is being organised more and more at a local level, closer to the people who need it.

Connections

The programme as a whole will provide points of action on these themes in terms of prevention, diagnosis and treatment, care and support, in both the short and the longer term. Collaboration will be a greater focus in phase 2, with questions being collected and answered, and the benefits applied in the best possible way in care and welfare practice. This will involve collaboration with parties in the field such as private care providers, and also with other ZonMw programmes, including the National

Care of the Elderly Programme (NPO) and the European Active and Assisted Living (AAL) programme. The use of knowledge is an important goal in phase 2. Memorabel will forge connections with the other main objectives of the Delta Plan for Dementia programme: improving care for people with dementia and creating a dementia-friendly society. New research questions will for example be gathered from practitioners and the public, research results disseminated and special communication activities launched.

Public Private Partnership

In phase 2 of Memorabel, as in phase 1, ZonMw will provide a proportion of the project budgets. Private resources will come from charitable funds and companies, for example. In this respect, Memorabel is in line with the Dutch government's top sectors policy.

ZonMw's relevance criteria can be adapted, further specified or extended in each call or programme activity. Since phase 2 of Memorabel includes public private partnership, ZonMw will stipulate additional requirements concerning the private contribution and mandatory agreements. Details will be presented in the calls for proposals.

Phase 2 priorities

In phase 2 Memorabel will focus on the further development of knowledge and on improving care and support for people with dementia. Biomedical and clinical research offers long-term prospects of dementia prevention and treatment for future patients. People with dementia and their informal carers benefit from improvements in the care and support currently provided on the basis of existing knowledge and innovations which can be deployed in the short term. The key focus of the programme is therefore integrated care (functional, medical, psychological and social) covering the entire knowledge chain (research, development, use of knowledge). The priorities under each theme are presented in no particular order.

Theme 1: Cause and mechanism of the disease

1.1 Understand the role of vascular factors, environmental factors, psychosocial factors and the immune system in the emergence of or protection from dementia, either individually or in interaction with genetic and epigenetic mechanisms.
1.2 Identify and understand genetic and epigenetic mechanisms of dementia – both risk-enhancing and protective – with the aid of new technology such as genome or exome sequencing, proteomics, metabolomics and synapse research, and by deciphering the molecular mechanism of rare, sometimes congenital, forms of Alzheimer's and other forms of dementia such as frontotemporal dementia, primary progressive aphasia, posterior cortical atrophy, Lewy body dementia etc.
1.3 Characterise the preclinical phase of dementia using imaging techniques (MRI, PET, MEG, EEG), brain fluid/blood and other biomarkers and neuropsychological tests, and combinations of these techniques.

Theme 2: Diagnosis

2.1 Identify predictive biomarkers that can predict the time to onset of clinical dementia, and allow the very early development of the disease to be monitored (e.g. on the basis of the connectivity of the brain and brain activity) and develop less invasive methods of determining brain damage (e.g. markers in the blood or retina) and/or monitoring the development of the disease and the effect of therapy.
2.2 Identify new disease pathways (via genetics and genomics, metabolomics, proteomics) and translate this information into diagnostic markers (proteins) for amyloid and non-amyloid beta aggregation on the basis of imaging techniques, blood and brain fluid analysis. The development of diagnostic markers for diseases other than Alzheimer's would also be consistent with this priority. Research into the impact of comorbidity on these disease pathways (e.g. Parkinson's, depression) in the various forms and subtypes of dementia would also be consistent with this priority. This might also include research into the differential diagnosis between various neurodegenerative diseases underlying dementia, and also into the difference with non-neurodegenerative differential diagnoses, such as psychiatric disorders.

2.3	Development of methods for identifying and diagnosing dementia at home, with a focus on arrangements between GPs and specialists, and on communication of results.
2.4	Harmonisation of diagnostic procedure (transfer of knowledge, sharing of best practice, gathering of questions from medical practice via the Dutch memory clinic network) would also be consistent with this priority.
2.5	Research into early diagnosis and its impact on quality of life, taking account of the prospects for treating symptoms and the disease.

Theme 3: Treatment and prevention

3.1	Identify new etiological risk and/or protective factors for dementia, with specific treatment implications, by monitoring populations of dementia sufferers (including early dementia) over time with rich phenotyping.
3.2	Research into and development of drug- and non-drug-based (e.g. psychosocial) interventions for people with dementia and their informal carers.
3.3	Innovative research into interventions and care and support concepts, including those focused on enhancing wellbeing and comfort.
3.4	Research into promoting active social participation; this might also include continued working.

Theme 4: Efficient care and support

4.1	Gain more understanding of the experience, preferences and needs of people with dementia, with a view to demand-driven care and value-based care, taking account of their life prospects.
4.2	Projects that support interdisciplinary collaboration in dementia care, and provide training and evaluation in the various phases of dementia (e.g. case management, organisation of care, variation in practice, small-scale initiatives). Support (including for informal carers) in the form of contact with fellow sufferers, housing, exercise, food, sleep, security, finances, IT/technology, for example, that helps patients retain their independence for as long as possible.
4.3	Multidisciplinary development and evaluation projects, collaboration, and transfer of knowledge and expertise concerning diagnosis existing among GPs in dementia care chains and dementia networks and in non-medical professions, with a specific focus on the structural role of the GP as part of a harmonised diagnostic procedure. Integration and coordination between indication and the various care and welfare payments (social support, sickness benefit and/or chronic care allowance). Intervention research using triage tools and Patient Reported Outcome Measures (PROMs) is, in practice, very important for good patient selection and effective evaluation among dementia patients, a group that is becoming steadily more diverse.
4.4	Research for a dementia-friendly society, focusing on the societal, physical and social setting and taking account of comorbidity.
4.5	The relationship between formal and informal care, including the development of collaboration models that fully reflect the contribution of patients' social network (including to residential care) and cost-effectiveness studies of informal care.
4.6	Take complex innovations that have already successfully completed one or more stages of development to the next stage of their evidence-based development through applied research.
4.7	Research into the ethical aspects of dementia, preferably as part of a larger study. This might include how to deal with declining decisional competence concerning treatment, for example, and also wills, abuse and assault.

ZonMw stimuleert
gezondheidsonderzoek en
zorginnovatie

Laan van Nieuw Oost-Indië 334
2593 CE Den Haag
Postbus 93245
2509 AE Den Haag
Telefoon 070 349 51 11
info@zonmw.nl
www.zonmw.nl

ZonMw