Excerpt from Memorabel programme document

Introduction
Dementia represents a major, and growing, challenge for society. As a result of demographic ageing, the number of people with dementia is set to rise sharply in the near future. A recent World Health Organization report estimated the global number of dementia sufferers at 35.6 million. If the extrapolations are correct (there is scientific evidence that the incidence is rising more slowly than expected) the number of dementia patients will have doubled by 2030, and more than tripled by 2050. A quarter of a million people in the Netherlands have dementia. One in five people develop dementia, and every year 7000 people die as a direct result of the disease. This makes dementia the third largest cause of death in the Netherlands. The number of people with dementia in the Netherlands is forecast to double to half a million by 2040.

We need a long-term national strategy to ensure the burden of caring for dementia patients remains manageable in the future. There is already a looming shortage of care workers and nurses to care for people with dementia. Many dementia sufferers are supported by informal carers, but the pressure on them is enormous. The costs are also high: at €4 billion a year in care costs (including the costs of accommodation when patients are institutionalised), dementia is the most expensive disease in the Netherlands, taking up more than 5% of the entire healthcare budget.

A national strategy is taking shape in the form of the Deltaplan for Dementia (www.deltaplandementie.nl), a nationwide public-private initiative that aims to tackle and manage the growing problem of dementia, using the Netherlands’ innovative strengths in science, product innovation and healthcare (including healthcare policy). The Deltaplan focuses on the Netherlands, but it also ties in well with the latest international developments and insights. Partners from both the public and private sectors have now committed to the plan.

The Deltaplan for Dementia aims for coordination, consolidation and implementation at national level, as the Dutch healthcare sector squares up to one of the greatest challenges it has ever faced. As such, the plan represents a cutting-edge approach that aims not only to improve understanding, treatment and prevention of dementia, but also to improve care and support for patients and informal carers. It consists of three elements:
1. **The Dementia Care Portal**
   An online platform for collaboration between professionals, patients and informal carers. As such, it is a vehicle for innovation and for implementation of the care standard, in collaboration with regional ‘chains’ of professionals and patients. The portal will bring together knowledge of and skills in dementia care. A care practice improvement programmes will be implemented as part of the care portal.

2. **National Dementia Register**
   Compiled by and for professionals, providing insight into the nature, scale, quality and development of dementia and dementia care in the Netherlands. It will also act as a tool for quality assessment.

3. **Dementia Research and Innovation Programme**
   An eight-year programme focusing on aetiology, diagnosis, prevention and treatment, and efficient care.

Details of the Research and Innovation Programme, which has been given the title ‘Memorabel’, are given below.

**Objective and themes**
There are many varieties of dementia; it is a heterogeneous disease, and different countries apply different definitions of dementia. Views as to how dementia should be dealt with also vary, although they are in essence complementary. Dementia interfaces with many sectors, areas of research and policies (on care, cure, prevention, housing, welfare). A huge number of organisations and professionals play a role in caring for and supporting people with dementia, and their involvement and expertise is very varied.

This means careful programming is required. Objectives and themes have therefore been drawn up for this research and innovation programme, and priorities for the first phase of the eight-year programme identified. These priorities will be updated in later phases of the programme.

This procedure is in line with the policy of practice-oriented programming that ZonMw has applied over the past few years. The priorities are based on specific questions and problems
from clients, on questions arising from research (knowledge gaps) and on questions arising from practice, and from the policy on care, support and prevention.

1.1. Objective

The goal of ‘Memorabel’ is 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) 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.
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.

1.2. Themes

The programme is divided into four themes:

1. Cause and mechanism of the disease
2. Diagnosis
3. Treatment and prevention
4. Efficient care and support

Given the objective, the programme will focus on developing new knowledge and on improving care and support for people with dementia. Biomedical and clinical research offers prospects of preventing and treating dementia in the long term. But people suffering dementia now will not benefit from this. They need improvements in current care and support in the short term, based on the further development of existing knowledge and innovations. The research and innovation programme will therefore focus on both today’s and tomorrow’s dementia patients.

- Research and development for tomorrow’s patients
  This concerns research and development activities within the above themes (with the exception of Efficient care and support) geared to prevention, early diagnosis, delay of
onset and treatment of dementia, and will generally lead to applicable results in the longer term.

- **Improvements in care for today’s patients**
  This concerns activities within the above themes (with the exception of Cause and mechanism of the disease) that help improve quality of life and contribute to efficient diagnosis, treatment, prevention, care and support in the short term, throughout the care, welfare and housing chain.

The priorities in the different themes will be updated regularly by – as is currently the case with JPND – drawing up a work plan every two years (from 2015).

The theme priorities for the first two-and-a-half years of the programme (2013-2015) have been set out in this programme document. They are shown in the table below, arranged depending on the degree to which and speed with which the priorities might lead to practically applicable results.
### 1.3. Theme priorities

<table>
<thead>
<tr>
<th>Theme 1: Origin and mechanism of the disease</th>
<th>Improvements in care of today’s patients – result applicable in <em>short</em> term</th>
<th>Research and development for tomorrow’s patients – result applicable in <em>long</em> term</th>
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<td></td>
<td>1.1 Identification and understanding of genetic and epigenetic mechanisms in dementia, using new technologies like sequencing, proteomics, metabolomics, synapse research.</td>
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<td>1.2 Understanding of the role of vascular factors, contextual factors and psychosocial factors in the emergence of or protection against dementia, either independently or in interaction with the factors mentioned at 1.</td>
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<td>1.3 Identification of new aetiological risk and/or protective factors for dementia by following large healthy populations over time using rich phenotyping screens. A vital part of this will be further characterisation of the pre-clinical phase of dementia using techniques such as imaging, imaging genetics, biomarkers, neuropsychological tests and other tests of brain function.</td>
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1.4 Unravelling of the molecular mechanisms of rare, sometimes hereditary, forms and subtypes of dementia (frontotemporal dementia, primary progressive aphasia, posterior cortical atrophy). This will also include research on individuals with a radically increased risk of dementia resulting, for example, from genetic predisposition and in order to develop better patient selection and stratification in trials and, ultimately, personalised treatment.

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<tr>
<th>Theme 2: Diagnosis</th>
<th>2.1 Acceleration of the diagnostic process when first symptoms occur and improvement of communication concerning diagnosis</th>
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<tr>
<td>2.2 Diagnostic tests (clinical, biomedical and neuropsychological for the various settings (different diagnostic approach at population level, primary care, secondary/tertiary care level) and identification of the net benefit of early diagnosis in practice, with focus on psychological and social factors and imperfections in diagnostic methods (incl. false positives and false negatives).</td>
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<td>2.3 Identification of new markers (blood, scans, cerebral fluid and DNA) that can be used as surrogate markers for presymptomatic to symptomatic stage.</td>
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<tr>
<td>2.4 Identification of new markers (blood, scans, cerebral fluid and DNA) for different forms of dementia, which predict the progression from presymptomatic to symptomatic stage.</td>
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## Theme 3: Treatment and prevention

| 3.1 Combination of psychosocial interventions for people with dementia and their informal carers, with a focus on social inclusion, strengthening of informal care, dealing with behavioural changes, prevention of neuropsychiatric problems and involvement of informal carers. |

| 3.2 Self-management for people with dementia and informal carers through development of e-health applications, technological applications (including domotics) and strategies for shared decision-making at key decision points during the course of the disease. |

| 3.3 Development of preventive interventions aimed at reducing risk in people with cognitive problems, genetic predisposition, and other well-defined risk groups, focusing on but not limited to vascular factors (and interactions between them), lifestyle factors (exercise, diet, smoking, sleep) and ageing. |

| 3.4 Development of medication-based interventions (plus combinations of new and existing interventions) to delay the disease and tackle emerging behavioural problems in different forms of dementia. This will include a focus on comorbidity and active participation in randomised clinical trials. |

## Theme 4: Efficient care and support

| 4.1 Identification of effectiveness (and cost-effectiveness) of available methods, interventions and instruments for diagnosis, treatment, care, housing and welfare. |

| 4.2 Identification of effectiveness (and cost-effectiveness) of the organisation of integrated dementia care, access to such care and its effects (incl. small-scale care settings, local care/daycare and support, residential care), with a view to implementation of the dementia care standard. |
| 4.3 Development of interventions that not only attempt to compensate for reduced function but, above all, focus on the existing capacities of people with dementia, their need for autonomy, their ability to contribute (reciprocity) and their dignity. |
| 4.4 Development of palliative care, with focus on care models, ethical issues and key elements of effective and cost-effective care. |
1.4. The Netherlands’ strengths

A great deal of expertise on dementia exists in the Dutch research sector. Dutch researchers have already achieved relevant results, and have a good international reputation. The programme wants to use this, where possible in an international context.

Dutch dementia research is particularly strong when it comes to phenotypical characterisation and follow-up data on large populations and patient cohorts. The Netherlands contributed to recent findings on the genetics of dementia. Besides studying the role of amyloid and tau in the emergence of Alzheimer’s, we have also long been involved in research into the role of vascular factors in dementia. Dutch scientists have made major breakthroughs in research into synapse function over the past decade. Researchers in the Netherlands are involved in both European and international partnerships working in these areas.

The Netherlands has a long track record of research into diagnostics (incl. MRI, CSF markers, new markers, development of new diagnostic criteria). Imaging research has produced promising results – as has biomarker research – and is thus a priority.

The large-scale epidemiological cohorts in the Netherlands offer excellent prospects for research into prevention.

Dutch researchers have been extremely productive in terms of psychosocial interventions, and are also well represented in European networks. The Netherlands is traditionally strong in efficiency research on dementia.

Other strong points include knowledge and experience of e-health, the recent development of care standards and GP guidelines, the Alzheimer Nederland organisation and the national programmes for the improvement of care of the elderly and dementia patients, such as the National Care of the Elderly Programme (NPO) and the National Dementia Programme.

The Netherlands also scores well in terms of infrastructure for clinical research. Large multicentre cohorts (both population-based and clinical) are another of the Netherlands’ strengths.
There are several large biobanks in the Netherlands, including that of the national Parelsnoer Institute (www.parelsnoer.org). The challenge for the coming period will be to strengthen and expand this infrastructure and the potential of biobanks.

The NPO networks, working with the dementia care chains, will provide a good channel for the application of new insights, guidelines and the care standard. The Netherlands’ colleges of higher education (hogescholen) have always had strong roots in the healthcare sector. They collaborate with healthcare organisations on a broad basis, and this enables them to focus their research on practice and the application of knowledge in healthcare and training.

1.5 ZonMw procedure

ZonMw issues calls for proposals for its research programmes. The first call for the Memorabel programme opened in October 2013. The first projects to be awarded grants will start in the summer of 2014. A second call will be issued later in 2014.