

Programme Document  
Dementia Research Programme  
2021-2030

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## **Publisher's details**

The Netherlands Organisation for Health Research and Development (ZonMw) promotes health research and care innovation.

Progress depends on research and development. ZonMw finances health research and promotes the use of the knowledge thus developed to improve healthcare and health.

ZonMw's main clients are the Ministry of Health, Welfare and Sport, and the Dutch Research Council.

For more information about our dementia research programme, please visit the website or contact us via email at [Dementie@zonmw.nl](mailto:Dementie@zonmw.nl).

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## Summary

On 21 September 2020, the Dutch Ministry of Health, Welfare and Sport (VWS) presented its National Dementia Strategy for the next ten years (2021-2030). The mission is to ensure that persons with dementia and their loved ones can continue to function as valuable members of society and receive appropriate support and care, and that sufficient scientific research is carried out into the possibilities for preventing, treating, and curing dementia. Part of this national strategy is the continuation and advancement of dementia research. ZonMw has been commissioned to set out a proposal for a Dementia Research Programme for the years 2021-2030. This programme will generate greater focus and synergy, and facilitate pioneering research to achieve breakthroughs in the prevention, diagnosis and treatment of dementia. The ZonMw research programme therefore focuses on the adequate treatment and/or improvements to the quality of life of people with dementia while working towards the ultimate goal: the prevention of dementia. This research programme builds on the previous ZonMw programme entitled *Memorabel* (Memorable), which since 2013 has provided the basis for funding research to advance national and international expertise in the field of dementia, from fundamental to applied research.

### A world without Dementia

A breakthrough is needed in the fight against dementia. This realisation is central to the National Dementia Strategy and to the research programming assignment that the Ministry of Health, Welfare and Sport has given to ZonMw. The National Dementia Strategy is structured in accordance with three main themes: 'A world without Dementia', 'Persons with dementia matter' and 'Tailor-made support when living with dementia'. Over the next ten years, the National Dementia Strategy will work to improve the quality of life of people with dementia and to obtain substantially greater knowledge about how we can better prevent, diagnose and treat dementia. This knowledge can make the difference in reducing the suffering and burden of dementia in the future. The government has made substantial funding available for this purpose, seeking active cooperation with funds and other private parties in order to make joint investments. The Dementia Research Programme is primarily focused on the first main theme: 'A world without Dementia'.

By 2030, we expect to achieve a deeper understanding of the causes of the disease and to have personalised treatment available for each patient. And we continue to hope for a breakthrough in terms of actually finding a cure for dementia. To reach this goal, we will stimulate and facilitate research in a range of fields, from fundamental research to patient-oriented studies. In taking this approach, we want to contribute to better prevention, earlier diagnosis, delayed progression and more effective treatment of dementia. This can reduce the suffering of patients and the burden of care on informal caregivers, and substantially improve quality of life.

The research programme builds on eight years of research under the banner of the *Memorabel* programme, which has yielded over 200 projects spread across research centres throughout the country, laying the foundation for sound cooperation with organisations such as Alzheimer Nederland and Health~Holland. These projects have not only helped improve care for today's patients, but have also enhanced our capacity to prevent, diagnose and treat the disease.

### Dementia Research Programme 2021-2030

#### Core objective

The Dementia Research Programme develops knowledge and contributes to the development of diagnostics and methods to prevent and treat dementia. This is achieved by incentivising and facilitating a high-quality research infrastructure based on insights from *Memorabel*, to connect socially relevant and high-quality dementia research. As a result, knowledge about causes, risk reduction (both general and personalised), diagnosis/prognosis and treatment of dementia will be generated and passed on more rapidly. In addition to knowledge development, the programme stimulates innovation and knowledge utilisation which should lead to the prevention of dementia and to a better quality of life for people with dementia and their loved ones, now and in the future.

The programme does this by formulating the core objective as three programme targets:

1. Existing and yet-to-be-developed knowledge, products, services and therapies will be made accessible, affordable and usable (i.e. applicable in human terms). Together with the two other main themes of the National Dementia Strategy, the programme encourages the transfer of results from the lab to education and ultimately to the physical and social living environment of the person with dementia and the people close to them (loved ones, caregivers and professionals/volunteers from the social domain) and vice versa.
2. The strengthening and embedding of an organisational, knowledge and data infrastructure that contributes to the sustainable development of knowledge and innovation regarding the origins, risk reduction, diagnosis, prognosis and treatment of dementia, now and in the future.
3. Forging links between national dementia research and international developments in the field.

## Programme strategy

The programme strategy consists of three core components. Firstly, the strategy is compartmentalised into six themes or domains that determine the direction and focus of the research programme. These are embodied in a series of work packages. Secondly, the strategy focuses on the realisation of knowledge, research and development infrastructure of the highest quality, which creates the conditions for pioneering research and innovation. The third component of the strategy focuses on the programming (strategic and otherwise), funding and implementation of pioneering research and innovation proposals by means of programme rounds.

### Work packages

Six work packages make up the core of the Dementia Research Programme:

- Work package 1            Fundamental Research
- Work package 2            Risk Reduction
- Work package 3            Diagnosis (and Prognosis)
- Work package 4            Promising Innovative Treatments
- Work package 5            Early Onset Dementia
- Work package 6            Knowledge Transfer: Integration of Education, Research and Care

These six work packages link to the three main themes and intersecting domains of the National Dementia Strategy, and form the research and development domains of the programme. Each work package focuses on an aspect of dementia research, with a multidisciplinary and broad research strategy that involves a range of research organisations, institutes and care institutions, operating jointly in consortia. There is a work package on fundamental research, on risk reduction and prevention, on diagnostics and prognostics, one on promising innovative treatments and one on early-onset dementia. In addition, there is a coordinating work package which links to all the others and is designed to provide a comprehensive basis for translational research and integration with the two other main themes of the National Dementia Strategy. Within this work package, data management will also be organised centrally and resources reserved for the development of a central platform for Open Science and FAIR data. This will connect, enrich and accelerate socially relevant and high-quality dementia research. It will also embed a sustainable infrastructure in terms of organisation, knowledge and data.

### Knowledge, research and development infrastructure

The Dementia Research Programme is designed to achieve synergy and focus, and therefore facilitates the development of a robust, high-performance and sustainable knowledge, research and development infrastructure. With this aim in mind, large-scale multidisciplinary partnerships known as research consortia will be formed in the Dementia Research Programme. In such a consortium, existing centres of excellence can enter into cooperation with other research groups and disciplines, with research institutes and health care institutions and/or companies, and/or with each other. These consortia are responsible for implementing the objectives of the work packages. Public-private consortia can also be formed to develop and market specific innovative methods of treatment. These may also include spin-off companies. To give them the capacity to respond to new insights gained in the course of the programme, consortia are permitted to adjust their focus and composition accordingly. This ensures that they have an agile and open character.

Consortia have expertise in all relevant domains of the research strategy, and are able to successfully bring knowledge and innovations through the various phases of a development cycle. They do this with a firm focus on the domain of the work package. The translation from laboratory to professional practice is key in this

process, i.e. the translation of knowledge into interventions in the areas of lifestyle, drugs, medical and biomedical technology and the organisation of care. Work package 1 Fundamental research is the only package where this translation is less central. Consortia also work to facilitate the further integration of the national knowledge infrastructure, for example in relation to personalised diagnostics, prediction and prevention of dementia, or to the transfer, upscaling and broad utilisation of newly developed knowledge and innovations that can contribute directly to a better quality of life for people with dementia and their loved ones. Both public and private parties need to be involved.

Preferably, the consortia should be given a regional implementation focus, so that care organisations, municipalities, and patient and client organisations can participate in the implementation and the scaling up of pioneering innovations. Such a focus is also conducive to the joint development of knowledge. This reflects the broader policy focus on implementation plans and the development of regional infrastructures (including Health-RI).

### **Programming and funding of research rounds and consortia**

When it comes to forming consortia, the sandpit method is the approach used. In the Dementia Research Programme, grants are deployed as a funding instrument to fund any preparatory activities in the run-up to the formation of a consortium, for example in the form of preparatory studies and incentive grants for initiating partnerships. Within each work package, proposals from one or from several consortia are selected and subsidised. A budget is also set aside to enable talented researchers to take their ideas a step further. Within each work package, an additional budget is reserved to support a demand-driven response to policy priorities or to facilitate links to research initiated beyond the remit of the programme. Specific criteria will be developed for this purpose. Dutch participation in rounds of grant funding organised by the worldwide Joint Programme – Neurodegenerative Disease Research (JPND) will be continued as part of the Dementia Research Programme.

In the course of the ten-year Dementia Research Programme, 140 million euros will be allocated in the grant funding rounds for each work package at different points in time, a phased approach that enables changes to be made to the content and the policies in order to achieve the most groundbreaking results.

### **Collaboration**

As part of the National Dementia Strategy, the Dementia Research Programme will work with the organisations behind the strategy's two other main themes: 'Persons with dementia matter' and 'Tailor-made support when living with dementia'. In the coming period, the relationship with the governance structure of the National Dementia Strategy (steering committee and executive committee) will also be worked out in greater detail. Work package 6 will form links between all the main themes and intersecting domains of the National Dementia Strategy. ZonMw is responsible for implementing the research programme on the basis of frameworks set by the steering committee and the executive committee. This also applies to projects backed by public-private partnership funding.

Public-private partnerships (within consortia) are a vital instrument for realising the objectives of the Dementia Research Programme. Collaboration of this kind is encouraged with a view to accelerating research and increasing impact. At the programme level, we will extend and strengthen existing partnerships with healthcare funds, such as Alzheimer Nederland, the Hersenstichting and the Gieskes-Strijbis Fonds. Cooperation with the Life Sciences & Health (LSH) top sector will also be reinforced. In these respects, programming will be mutually coordinated. Projects (and results) can be passed on and jointly financed. The above parties are encouraged to become involved, as are other private and commercial parties. This involvement may concern a consortium that is taking shape and at the project level. ZonMw operates on the principles of Open Science and Socially Responsible Licensing. Open Science includes FAIR data and data management, Open Access, recognising and rewarding researchers, and citizen science. In the Dementia Research Programme, we work with Health-RI to ensure that research data meets the FAIR principles. The aim is to achieve the necessary conditions as regards data interoperability, both for future research and validation, and for implementation and upscaling. All research data, services and products must comply with FAIR data principles and Open Access standards.

Finally, the Dementia Research Programme will ensure integrated communication and coordination with regard to dementia, people with dementia and their loved ones. This will be achieved through a range of ZonMw programmes.

### **Progress reports**

ZonMw reports periodically to the steering committee and the executive committee of the National Dementia Strategy. The commissioning party for the programme – the Ministry of Health, Welfare and Sport – will be kept informed of progress in accordance with the working agreements in force. The Dementia Research Programme aims to conduct two interim evaluations and a final external evaluation. In addition to regular monitoring and in accordance with ZonMw grant conditions, separate monitoring and coordination agreements will be made with the consortia.

# 1 Introduction

*‘There are currently about 280,000 people with dementia in the Netherlands. This number is expected to rise to about 420,000 in 2030 and 520,000 in 2040. The costs of dementia care will increase accordingly: from €6.6 billion in 2015 to €15.6 billion in 2040. This means that dementia is on the path to become the main cause of death in the Netherlands, and the most expensive disease as well. Since 2004, the Ministry of Health, Welfare and Sport has been working on the theme of dementia with three successive programmes: the National Dementia Programme (2004-2007), the Integrated Dementia Care Programme (2008-2012) and the Dementia Delta Plan (2013-2020). The above developments are important reasons for the Ministry to not only continue its efforts in the fight against dementia, but to intensify them from 2021 onwards in the form of the National Dementia Strategy 2021-2030. For many years now, ZonMw has been developing knowledge to improve our understanding of dementia, provide points of reference for treatment and improve both new and existing care interventions.<sup>1</sup> On 21 September 2020, the Dutch Ministry of Health, Welfare and Sport presented its National Dementia Strategy for the next ten years (2021-2030) with the above introduction. The strategy covers three themes: ‘A world without Dementia’, ‘Persons with dementia matter’ and ‘Tailor-made support when living with dementia’.*

ZonMw has been contributing to the search for solutions for dementia for many years now, in particular with the *Memorabel* programme (from 2013). This programme has granted funding to almost 200 national and international projects since 2013. The interim evaluation confirms how these projects have contributed to more knowledge on prevention and on the origins and mechanisms of dementia. Unfortunately, there is no cure yet, but diagnostic procedures have improved considerably and care and support have been enriched with interventions and knowledge about the effects of care and welfare. We now know more about the influence of lifestyle, our understanding of the causes of dementia has improved, researchers are cooperating more, and a foundation has been laid for the development of drugs that will hopefully be able to prevent or slow down the disease in the future. People living with dementia now receive more personalised care and more proven effective treatments. The digital publication<sup>2</sup> *‘De opbrengsten van Memorabel; 8 jaar dementieonderzoek’* (2020) (‘The benefits of *Memorabel*; 8 years of dementia research’) provides examples of projects and overviews of all the studies, as well as stories of successful patient interventions developed through the programme so far. A number of projects are still ongoing.

<sup>1</sup> <https://www.rijksoverheid.nl/documenten/publicaties/2020/09/21/nationale-dementiestrategie>

<sup>2</sup> <https://publicaties.zonmw.nl/memorabel-projectresultaten/>



## 2 Objective and scope

This section describes the starting points and objectives of the Dementia Research Programme 2021-2030 and explains the intended results and the scope of the programme. The objectives have been formulated on the basis of the policy and research agendas and starting points.

### 2.1 Starting points

The following starting points form the basis of the Dementia Research Programme:

- The Dementia Research Programme has been established to bring more focus to the research on dementia and encourage more synergy through the funding of several multidisciplinary consortia. The dementia research is coordinated under the umbrella of this multidisciplinary infrastructure. The investment enables significant improvements in the organisation of dementia research and the development of the required knowledge and data infrastructure.
- The existing, high-quality research centres for dementia research are encouraged to form effective consortia with relevant parties in the field of dementia.
- The Dementia Research Programme strives to improve cooperation between the three themes of the National Dementia Strategy and encourage a proactive approach to the intersecting themes of this strategy. The agreements with other implementing parties of the strategy will be worked out in more detail as soon as more is known. ZonMw has close working relationships with other research initiatives based on regularly coordinated cooperation agreements.
- The programme focuses on the themes of Fundamental Research, Risk Reduction, Diagnostic Procedures and Promising Innovative Therapies. These themes comprise four of six work packages within the programme. The four 'Ds' of Drugs, Diagnostics, Data and Devices play an important role in the development of innovative therapies where applicable.
- All four aforementioned work packages of the Dementia Research Programme focus on the development of medical and data-driven technologies (MedTech). Public-private partnerships play a crucial role in enabling the further development of innovative therapies in the Promising Innovative Therapies work package.
- Integrating research, care and education is fundamental to ZonMw's work. Knowledge development is secured in healthcare practice by, for example, including a compulsory impact plan in the project application phase, appointing a knowledge manager at the start of all projects and monitoring and adjusting knowledge development activities throughout the term of the project. A member of the programme committee will also be appointed with this theme in his or her portfolio.
- A communication plan is drawn up for each stakeholder as part of the communication strategy, whereby relevant knowledge is shared with at-risk groups. The Risk Reduction work package pays specific attention to informing the target group of potential ways of reducing the risk of dementia.
- All research activities within the programme are carried out under the Open Science and FAIR data principles. In addition, all research is designed with due regard to providing '[room for the talent of every individual, with respect for the principle of fair recognition and appreciation of researchers](#)'.
- The Dementia Research Programme will contribute to 'mission IV' of the Ministry and the relevant activities conducted through the Life Sciences and Health top sector and harmonise its activities accordingly. The programme will be coordinated with the relevant grant rounds of the KIC. Cooperation agreements will be made at the programme level with Health~Holland, Alzheimer Nederland and the Dutch Brain Foundation. Cooperation with and joint funding by private parties at the project level is encouraged for all projects and compulsory in a number of cases. The principle of socially responsible licensing is the starting point for the development of new therapies.
- The substantive and financial contributions to the JPND have been designated and budgeted. ZonMw proposes interim evaluations after three and six years and a final evaluation at the end of the programme.
- An independent programme committee will be appointed for the programme. The responsibilities of the programme committee are aligned with the responsibilities of the executive and steering committees (this will be worked out in more detail).
- The programme committee will ensure that resources are equally distributed among the work packages and is responsible for targeted and integral portfolio management across the programme aimed at encouraging the various consortia to achieve the maximum output.

## 2.2 Goals of the Dementia Research Programme

Dementia is the name given to a combination of symptoms (i.e. a syndrome) that inhibit the capacity of the brains to process information. This leads to changes in behaviour and the deterioration of thinking skills. More and more people suffer from dementia and it is on the way to becoming the most common and costly disease and a major social problem<sup>3</sup>. The Dementia Research Programme is an elaboration of one of the three key themes of the National Dementia Strategy: 'A world without Dementia'. This key theme has been translated in the National Dementia Strategy into the goal for 2025 to provide every person with dementia a tailored diagnosis and a treatment plan aimed at and adapted to their needs. Another goal for 2025 is to gain more insight into what causes dementia (in addition to the current knowledge that around 40% of dementia cases could have been prevented by lifestyle changes). The Dementia Research Programme is not only focused on developing theoretical knowledge in this area, but also aims to achieve real impact by encouraging knowledge and innovations in working practice.

The risk of dementia varies from person to person, as does the form of dementia. The disease can begin at almost any age, and its course may vary from person to person. However, there are several phases that occur in all patients. The field of diagnostics has particularly improved in the last ten years, but there are still people who do not seek help when they suspect dementia due to a lack of treatment options. Finding the right treatment for each individual is made much easier with improved diagnostic procedures.

The Dementia Research Programme focuses on various research and development domains within dementia research. The fundamental research carried out under work package 1 develops knowledge about the causes of and mechanisms that lead to dementia. The research into risk reduction under work package 2 attempts to improve our understanding of potentially influenceable dementia risk factors and the role of protective factors herein. This work package also aims to facilitate the further development of effective preventive interventions. A separate domain focuses on the search for new early diagnosis methods (work package 3) and starting points for the development of treatments. The programme encourages the development and implementation of innovative therapies (work package 4) for the benefit of the patients. In addition, the programme focuses specifically on young dementia patients (work package 5) and is committed to translating research knowledge into practice and the integration of care, research and education (work package 6).

The Dementia Research Programme pays specific attention to young researchers through the allocation of talent grants. The programme also has an international aspect, whereby cooperation is funded with the aim of enabling Dutch researchers to participate actively and meaningfully in international dementia research. ZonMw will ensure that the knowledge developed as part of this programme is made accessible according to the principles of Open Science and FAIR data. A communication strategy will also be developed in collaboration with the stakeholders and in coordination with the other themes of the National Dementia Strategy.

The Dementia Research Programme contributes to these research and development domains with the aim of improving the quality of life of people with dementia through various interventions.

The core objective of the programme is as follows:

The Dementia Research Programme develops knowledge and contributes to the development of diagnostics and methods to prevent and treat dementia. This is achieved by incentivising and facilitating a high-quality research infrastructure based on insights from *Memorabel*, to connect socially relevant and high-quality dementia research. As a result, knowledge about causes, risk reduction (both general and personalised), diagnosis/prognosis and treatment of dementia will be generated and passed on more rapidly. In addition to knowledge development, the programme stimulates innovation and knowledge utilisation which should lead to the prevention of dementia and to a better quality of life for people with dementia and their loved ones, now and in the future.

The programme does this by formulating the core objective as three programme targets:

1. Making the knowledge, products, services and therapies that are developed more affordable and widely applicable for the people that need them. Together with the two other main themes of the National Dementia Strategy, the programme encourages the transfer of the results from the lab to education and

<sup>3</sup> <https://www.vektis.nl/intelligence/publicaties/factsheet-dementie>

ultimately to the physical and social living environment of dementia patients and the people close to them (loved ones, caregivers and social care professionals and volunteers) and vice versa.

2. The strengthening and embedding of an organisational, knowledge and data infrastructure that contributes to the sustainable development of knowledge on causes, risk reduction, diagnosis, prognosis and treatment of dementia, now and in the future.
3. The Netherlands participates actively and meaningfully in international dementia research.

These three goals are central to the entire Programme Document and form the basis for the design of the Dementia Research Programme. The elaboration of the goals and how the programme will achieve them is explained in the following sections. The first goal is elaborated below and also (among others) in the establishment of large consortia that focus on specific work packages as described in *Section 4:*

*Implementation of the Programme.* The second goal is mainly elaborated in work package 6 and further explained in *Section 10: Communication and Implementation* (not included in this version of the Programme Document). The third goal is addressed throughout the Programme Document as well as in a more detailed explanation in *Section 2: Context of the Programme, International Developments.*

### **2.3 Quality of life of people with dementia**

The work packages of the Dementia Research Programme aim to improve the quality of life of people with dementia through various interventions. Fundamental research will lead to a better understanding of the mechanisms and the course of this disease. Such research forms an indirect but indispensable foundation for the programme. Reducing the risk of dementia will ultimately lead to more years of good health and fewer sufferers of the disease in the future. Improvements in personalised diagnostics offer opportunities for earlier and more targeted treatment and support that can make the disease more bearable. Finally, promising innovative therapies, such as new technologies, can directly improve the quality of life of people with dementia and their loved ones.

### **2.4 Knowledge cycle and the role of public-private partnerships**

In the knowledge cycle (figure 2) of development, pre-application, implementation and monitoring, relevant knowledge about origins, risk reduction, diagnostics, prognostics and treatment and support for dementia is developed together with professionals in the field. Such knowledge is only relevant if it answers the needs of the practicing professionals and their patients. The Dementia Research Programme therefore encompasses the entire knowledge cycle, whereby ZonMw is responsible for facilitating knowledge development and transfer and encouraging implementation in practice (knowledge utilisation). The professional field is responsible for the actual application of the knowledge in practice and education. The Dementia Research Programme will also identify and record the requirements of the professional field. The programme will be coordinated with other programmes such as Alzheimer Nederland that also aim to improve the care and well-being of dementia patients in practice. Alzheimer Nederland published a research agenda in 2020 that revealed that people with dementia, their families and their healthcare professionals have questions that require more fundamental research in order to be answered.

Among others, this concerns technologies, whereby the business community could be involved starting from Technology Readiness Level (TRL) 2, while healthcare providers could also be involved from TRL 5. The Future Affordable & Sustainable Therapies (FAST) approach and the principles of Socially Responsible Licensing are applied here, just as with the development of drugs.

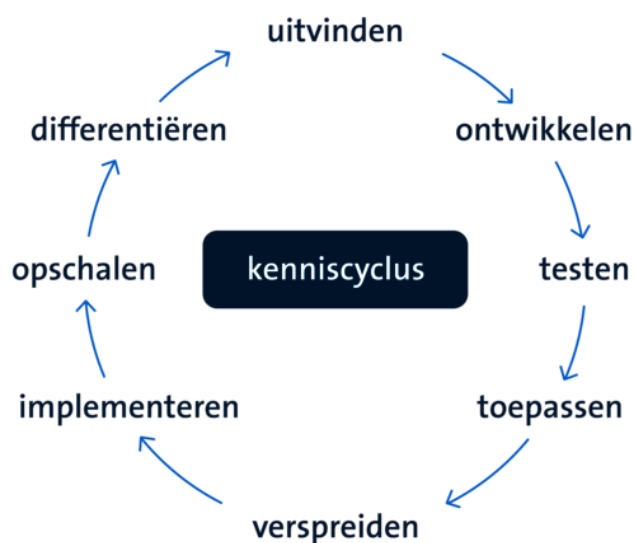


Figure 2: Knowledge Cycle

## 2.5 Results

The intended results at the end of the programme are as follows.

1. The research has contributed to:
  - Government policies (missions) aimed at reducing the risk of dementia<sup>4</sup>.
  - The development of effective and efficient treatments.
  - The development of new preventive interventions, diagnostic procedures and treatments.
  - The implementation of more safe, effective and affordable healthcare interventions.
  - More knowledge of indications for promising treatment strategies in different forms of dementia.
  - More and better knowledge-based guidelines and approaches that enable professionals to work together at the national and local level to combat dementia and contribute to quality of life.
  - More knowledge of early onset dementia.
2. A national organisational, knowledge and data infrastructure for dementia research has been established and is used by all relevant parties.
3. The Netherlands participates actively and meaningfully in international dementia research and implements the knowledge for the benefit of people with dementia, their loved ones and future dementia patients in the Netherlands.
4. By strengthening the dementia knowledge infrastructure, the programme produces a flywheel effect and so improves the position of the Netherlands in the field of research and innovation and in the market for technologies and therapies.
5. All data are subject to the FAIR principle and the research results are developed according to Open Science principles, ensuring that the knowledge and data generated through the programme are widely applicable.

Diagnostic tools and lifestyle interventions, pharmacological therapies and technologies are translated and transferred to working practice based on fundamental research results. This research is performed as part of work packages that focus on risk reduction, diagnostics and innovative treatments.

## 2.6 Scope

The Dementia Research Programme focuses on research and innovations in risk reduction, early diagnosis, prognosis and treatment. The programme generates knowledge that can be used to develop or personalise

<sup>4</sup> The outcomes formulated in the National Dementia Strategy, i.e. to develop socially relevant and high-quality knowledge about dementia such that: 1) by 2025, every person with dementia can receive a tailored diagnosis and a treatment plan aimed at and adapted to their needs, and 2) by 2025, more insight has been gained into what causes dementia in the 60% of patients in the 'other' group (based on the current knowledge that around 40% of dementia cases could have been prevented by lifestyle changes). The goal is to have built a comprehensive understanding of these causes by 2030.

treatments and other interventions. These interventions involve all diagnostic, therapeutic, care and support activities in the healthcare and social domain, including all diagnostic and prognostic procedures, pharmacological therapies, surgical interventions, the application of medical technologies and devices, and interventions aimed at risk reduction. The programme also focuses on applications in general practice care, public health, care provided by geriatricians and specialists in geriatric medicine, paramedical care, nursing care, mental health care (GGZ), palliative care and the social domain.

The Dementia Research Programme encompasses the entire knowledge cycle, whereby the fundamental research must have a substantiated relationship with dementia. This means that, for example, curiosity-driven physics research is excluded from the programme. Methodological research projects (e.g. to study the use of artificial intelligence or risk reduction measures) are only eligible for a grant if they contribute to answering a dementia research question. The impact on quality of life must always be substantiated in all project applications.

### 3 Strategy of the research programme

This section outlines the approach by which the Dementia Research Programme aims to achieve its objectives.

#### 3.1 Action plan

The research strategy consists of three core components. Firstly, the strategy is divided into six themes (work packages) that establish the direction and focus of the research programme. Secondly, the strategy focuses on building a knowledge and research infrastructure of the highest quality which creates the conditions for pioneering research and innovation. The third component of the strategy focuses on programming, funding and implementing pioneering research and innovation proposals by means of programme grant rounds.

##### Research and development domain

The Dementia Research Programme is structured around six work packages, each with a specific focus and a shared goal. The work packages focus on:

1. Fundamental Research
2. Risk Reduction
3. Diagnostics (and Prognostics)
4. Promising Innovative Therapies
5. Early Onset Dementia
6. Knowledge Transfer: Integration of Education, Research and Care

In work packages 2 to 5, an important role is set aside for translating interventions in the field of lifestyle, drugs, biomedical and medical technology into practice. Target group participation plays an important role in all work packages and is elaborated in Section 5. The combined work packages are linked through a coordinating work package (6). This is where the programme will be brought together. This work package will also be used to jointly ensure translation into practice and education, integration, effective organisation, data management and upscaling of the results that are made accessible based on the principles of Open Science and Socially Responsible Licensing. Work package 6 will also be used to reinforce the links with the two other themes of the National Dementia Strategy. See Figure 3 for an organizational chart depicting the three core themes of the National Dementia Strategy, the development of dementia and the six work packages.

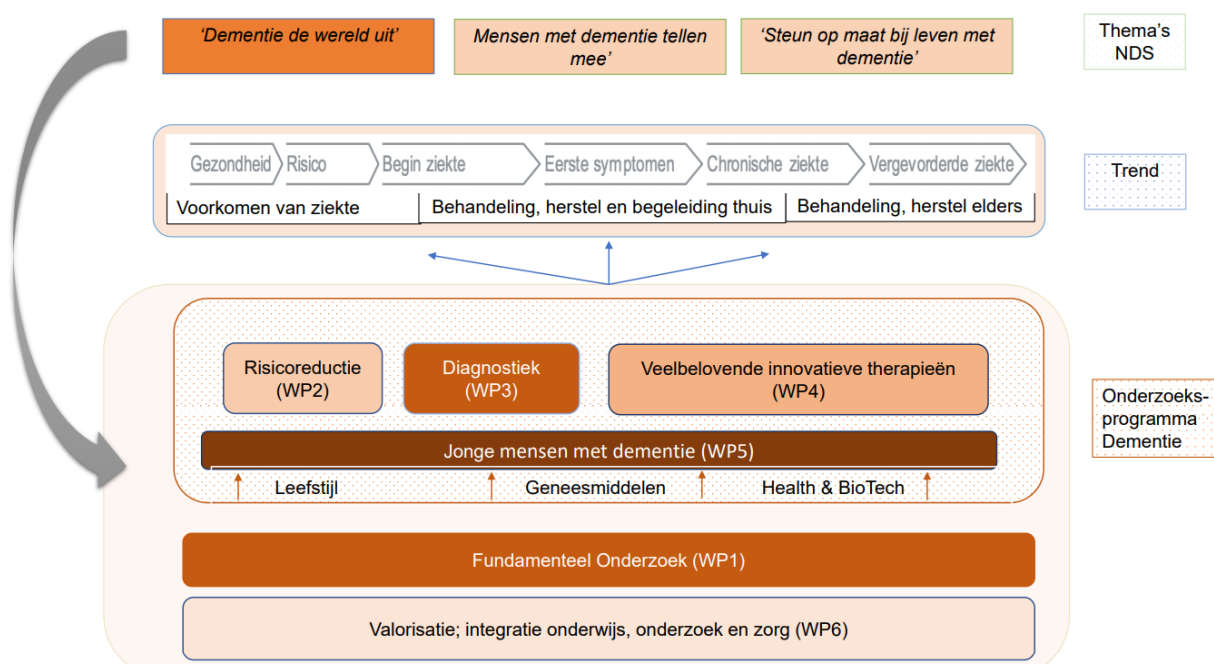


Figure 3: Core themes of the National Dementia Strategy and the six work packages of the Dementia Research Programme

These six work packages link to the three main themes and intersecting domains of the National Dementia Strategy. Each work package focuses on an aspect of dementia research, with a multidisciplinary and broad research strategy that involves a range of research organisations, institutes and healthcare institutions, operating jointly in consortia.

#### **Building an excellent knowledge, research and development infrastructure (role of/for the consortia)**

The Dementia Research Programme is designed to achieve synergy and focus, and therefore facilitates the development of a robust, high-performance and sustainable knowledge, research and development infrastructure. With this aim in mind, large-scale multidisciplinary partnerships known as research consortia will be formed in the Dementia Research Programme. In such a consortium, existing centres of excellence can enter into cooperation with other research groups and disciplines, with research institutes and healthcare institutions and/or companies, and/or with each other. These consortia are responsible for implementing the objectives of the work packages. Public-private consortia can also be formed to develop and market specific innovative therapies (these may also include spin-offs). To give them the capacity to respond to new insights gained in the course of the programme, consortia are permitted to adjust their focus and composition accordingly. This ensures that they have an agile and open character.

Various research groups in the Netherlands are working on one or more elements of dementia research. The programme aims to bring these groups together, enrich them by involving other disciplines in their work (such as behavioural sciences and humanities), and organise them into powerful consortia that can contribute to achieving the objectives of the programme and the specific goals of the work packages. Most of the involved centres have broad expertise and will likely participate in several consortia. Each consortium will be represented by a coordinating party (preferably one with a focus on regional implementation).

Consortia have expertise in all relevant domains of the research strategy, and are able to successfully bring knowledge and innovations through the various phases of a development cycle, which can then be deployed for the theme/research domain of the work package carried out by the relevant consortium. The translation from laboratory to professional practice is key in this process, i.e. the translation of knowledge into interventions in the areas of lifestyle, drugs, medical and biomedical technology and the organisation of care. Work package 1 (Fundamental Research) is the only package where this translation is less central to the programme. Consortia also work to facilitate the further integration of the national knowledge infrastructure, for example in relation to personalised diagnostics, prediction and prevention of dementia, or to the transfer, upscaling and broad utilisation of the developed knowledge and innovations. Both public and private parties need to be involved.

Preferably, the consortia will focus on regional implementation, so that healthcare organisations, municipalities, and patient and client organisations can participate in the implementation and the scaling up of pioneering innovations. Such a focus is also conducive to the joint development of knowledge. This also reflects the broader policy focus on regional implementation plans and the development of data infrastructures (including Health-RI).

#### **Method of programming, linking and funding**

In the Dementia Research Programme, grants are deployed as a funding instrument to fund any preparatory activities in the run-up to the formation of a consortium, for example in the form of preliminary studies and incentive grants for initiating partnerships. Consortia can submit proposals for the call and/or specific objectives of the various work packages. Proposals from one or several consortia are selected and funded per work package or research round.

A budget is also set aside to enable talented researchers to take their ideas a step further. The principles of *Recognising and Appreciating*, as described in the position paper entitled [‘Ruimte voor ieders talent; naar een nieuwe balans in het erkennen en waarderen van wetenschappers’](#) (‘Room for the talent of every individual; towards fair recognition and appreciation of researchers’), will be applied to the research of both the consortia and the fellowships. Within each work package, an additional budget is reserved to support a demand-driven response to policy priorities or to facilitate links to research initiated beyond the remit of the programme. Specific criteria will be developed for this purpose. Dutch participation in rounds of grant funding organised by the worldwide Joint Programme –

Neurodegenerative Disease Research (JPND) will be continued as part of the Dementia Research Programme.

During the course of the ten-year Dementia Research Programme, a total of €140 million will be allocated in the grant funding rounds for each work package and spread over a given period. This phased approach will enable the programme content and policy to be adapted in order to achieve the most effective results.

## 3.2 Work packages

The National Dementia Strategy has identified specific targets, themes and intersecting issues. These have been translated into a core objective and three specific goals for the Dementia Research Programme. The Dementia Research Programme has been divided into six work packages to elaborate these themes. The Programme thus facilitates, accelerates and links socially relevant, high-quality dementia research that contributes to our knowledge of the causes of dementia, personalised risk reduction measures, diagnostics/prognostics and the treatment of dementia. Each work package has its own focus and, if necessary, research strategy. Public-private partnerships are also encouraged in all the work packages. How this is implemented may differ per work package. Figure 3 displays a schematic representation of the work packages. The specific focus of each of the six work packages is briefly explained below. The various research activities that can be deployed per work package are further explained in Section 4 (Implementation of the Programme).

### Work package 1: Fundamental Research

The Fundamental Research work package focuses on the development of knowledge of the causes and mechanisms that lead to dementia. This knowledge is needed in order to eventually find a treatment for the various diseases that cause dementia, such as Alzheimer's disease, frontotemporal dementia, primary progressive aphasia, posterior cortical atrophy and Lewy body dementia. Fundamental research focuses on the molecular level, the cellular level and the neural networks in the brain. This includes research into genes, nerve cells, glial cells, proteins, fats, immune and inflammatory responses, the vascular system and the blood-brain barrier. Identifying and understanding genetic and epigenetic mechanisms of dementia (both their risk and protective factors) with the help of new technologies also falls under this work package. Examples include genome or exosome sequencing, proteomics, metabolomics and synapse research. Research projects and consortia in this work package must ensure the research is translated into practice and make explicit links with translational research expertise and pathways.

### Work package 2: Risk Reduction

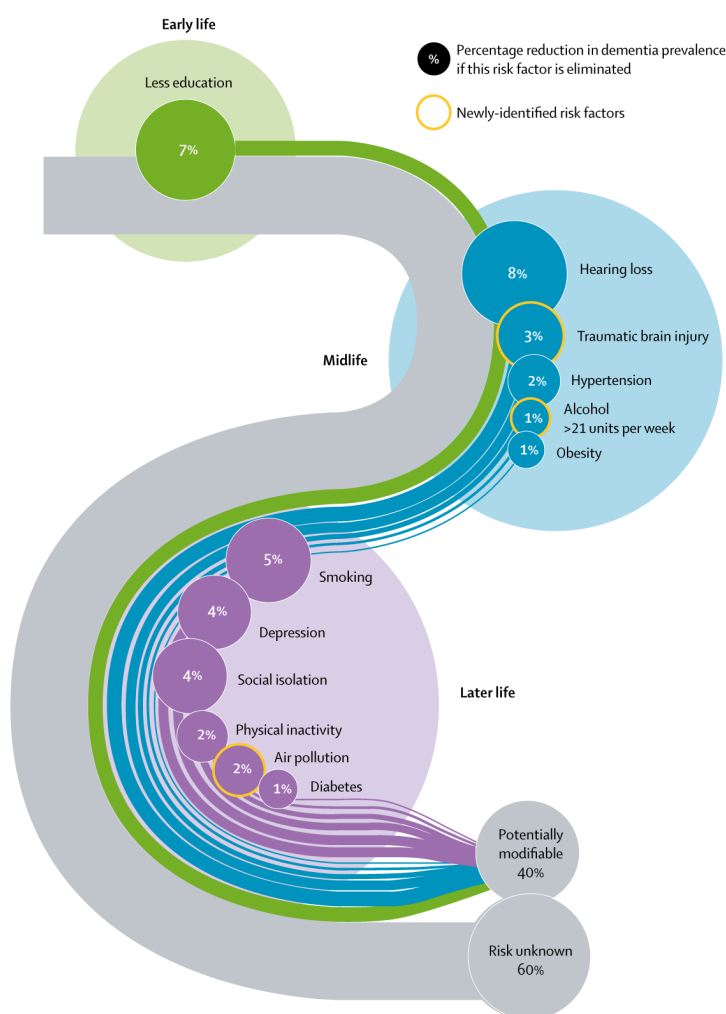
The Risk Reduction work package focuses on developing knowledge of influenceable risk factors of dementia and the role of protective factors and their implementation. This research will focus on target groups, phases of illness, types of measures and methods of implementation. In addition, more insight is needed into the effectiveness of interventions aimed at influencing these factors, for example, in order to prevent a worsening of the disease in people with dementia. The programme can thus help prevent and/or alleviate suffering in existing patients. Ultimately, the best way to eliminate dementia is to prevent the disease from occurring. Risk reduction is aimed at promoting and protecting health and preventing diseases and complications.

The latest research indicates that around 40% of dementia cases could have been prevented by positively influencing lifestyle factors (see also Figure 4, published in *The Lancet* in 2020<sup>5</sup>). A goal of the National Dementia Strategy is to gain more insight into the causes that lead to the remaining 60% of dementia cases by 2025. The research in this work package will contribute to achieving this goal.

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<sup>5</sup> Dementia prevention, intervention, and care: 2020 report of the Lancet Commission - *The Lancet*.





Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet* 2020.

Figure 4: Prevention of Dementia

Universal risk reduction focuses on influencing the lifestyles of the general population. In work package 2, this will be carried out in conjunction with ongoing studies where possible (such as the FINGER study, a long-term lifestyle intervention study with local initiatives worldwide).

This work package can also encompass research in the field of selective risk reduction (which focuses on specific risk groups) and indicated risk reduction measures (for individual patients). Social networks, GPs, nurses, carers and paramedics play a role in early detection of the disease and the deployment of indicated risk reduction measures. This work package will also invest in this risk reduction pathway to directly help people with dementia. Healthcare research aimed at improving the organisation of care, and thus the quality of life of people with dementia, also falls under this work package.

Genetic research will contribute to improving indicated risk reduction measures. By clearly defining risk target groups, potential interventions can be identified in the experimental phase. To facilitate this, this work package will also pay attention to the development of indicated interventions, e.g. in the form of a vaccine, drug or RNA modification which could prevent, delay, stop or slow down the disease. Such interventions will enable people with a genetic risk of developing dementia to be treated in the future.

Research into ways of reducing the risk of dementia can be done in conjunction with fundamental research. If necessary, a consortium can be expanded to include the targeted development of a promising innovative therapy.

New findings and knowledge developed through this work package, such as information on how to reduce the risk of dementia, will be disseminated and communicated using specific communication strategies appropriate for the target group. This will be done in cooperation with the other core themes of the National Dementia Strategy and any other relevant parties.

### **Work package 3: Diagnostics (and prognostics)**

The Diagnostics work package focuses on identifying predictive biomarkers, and on developing and improving less invasive methods of determining brain damage. This makes it possible to detect the earliest signs of development of the disease and to monitor the progress of the disease and the effect of therapies. It is important to continue this development of diagnostic procedures, because the treatment of dementia is highly dependent on early diagnosis.

The deployment of medical technologies and biotechnology in diagnosis (and early diagnosis) will also be addressed in this work package. Future treatments of dementia will also depend on the specificity and sensitivity of these diagnoses. It is expensive to implement a treatment intervention in a large population over a long period of time. This development will therefore have a profound impact on the overall cost of dementia.

New findings and knowledge developed through this work package, such as the potentials of new diagnostic procedures, will be disseminated and communicated using specific communication strategies appropriate for the target group. This will be done in cooperation with the other core themes of the National Dementia Strategy and any other relevant parties.

### **Work package 4: Promising Innovative Therapies**

The Promising Innovative Therapies work package aims to bring specific innovative therapies to the market as far and as fast as is possible and implement them. The four ‘Ds’ of Drugs, Diagnostics, Data and Devices play an important role in the development of innovative therapies where applicable. These are the ‘high potential ground-breaking innovations’, ranging from therapies involving artificial intelligence to social interventions. This contributes to the programme’s goal of bringing knowledge, products, services and therapies to people living with dementia and the people close to them more quickly and thus improving their quality of life.

Public-private partnerships play an important role in several work packages of the Dementia Research Programme, in cooperation with Health~Holland. This approach is central to work package 4. The expertise of the ZonMw’s Life Sciences & Health cluster is involved in these public-private partnerships. This cluster has experience with the Netherlands Genomics Initiative (NGI) and cooperates with the Netherlands Enterprise Agency (RVO). In addition, the methodologies of Health~Holland (LSH) are deployed and those of FAST may also play a role in the future.

For example, the development of pharmacological therapies for dementia usually involves a public-private partnership from the translational phase onwards. Currently, there are no pharmacological therapies that can cure dementia. Potential drugs for treating Alzheimer’s are in various stages of development and research (see Figure 5). Work Package 4 focusses on therapeutic interventions in later stages of development, i.e. translational research. This can include upscaling and implementation once an intervention has been approved.

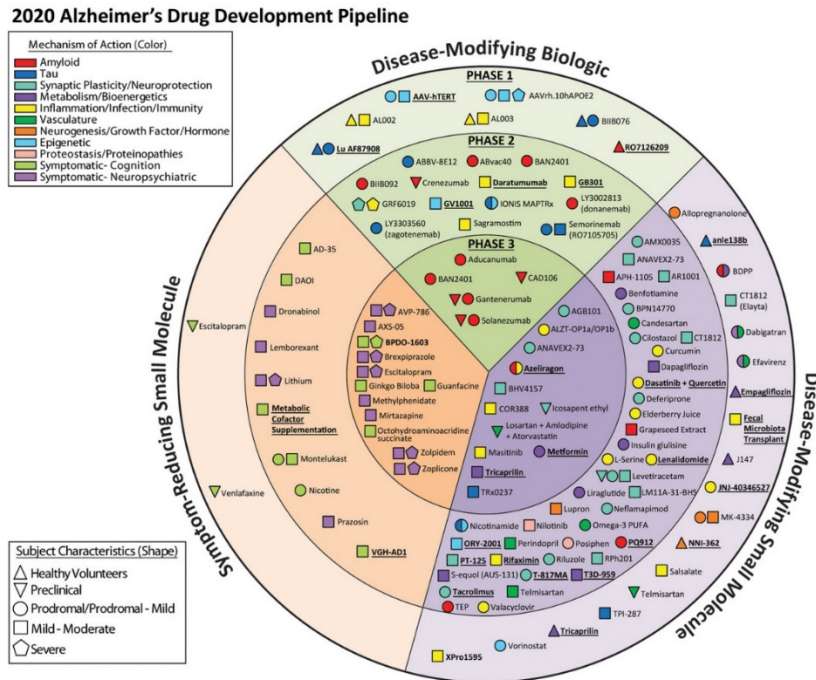


Figure 5: Alzheimer's Drug Development Pipeline

To reduce the costs of therapy development and use the available research capacity more efficiently, alternative methods must be sought to identify which new treatments have real potential at an early stage. FAST aims to achieve this by facilitating experiments with and continued development of models and methodologies for translational research. The Dementia Research Programme will adopt the FAST approach and preferably use the translational method currently under development. This will enable the expertise to be put to use to reach agreements on intellectual property with interested parties at an early stage. Appropriate public-private and commercial partnerships can be sought in the various phases of drug research, whereby the Dementia Research Programme stands for the principles of Socially Responsible Licensing.

Research into off-label use of existing technologies and therapies for dementia can also take place within this work package. Innovations must be underpinned by knowledge of cost-effectiveness and a budget impact analysis, and a clear path to professional practice must be indicated.

New findings and knowledge developed through this work package, such as information about new pioneering therapies, will be disseminated and communicated using specific communication strategies appropriate for the target group. This will be done in cooperation with the other core themes of the National Dementia Strategy and any other relevant parties.

**Work package 5: Early Onset Dementia**

Early onset dementia (dementia in people under 65 years) has been designated an intersecting theme within the National Dementia Strategy. The group of young people with dementia is growing, and these patients often have a different type of dementia than people over 65. This work package facilitates fundamental research and the development of diagnostic knowledge aimed at this specific target group. This group is of great importance in the search for new treatments, as they often have a 'pure' form of dementia, without comorbidity or other causes behind their symptoms. This makes it possible to study the effects of new treatments in this group. Because they are in a different stage of their life, dementia has a different impact on this group than on older people. The programme will also facilitate the development of knowledge on personalised care for this target group.

New findings and knowledge developed through this work package, such as new insights into the causes of early onset dementia, will be disseminated and communicated using specific communication strategies appropriate for the target group. This will be done in cooperation with the other core themes of the National Dementia Strategy and any other relevant parties.

### **Work package 6: Knowledge Transfer: Integration of Education, Research and Care**

The work package 'Knowledge Transfer: Integration of Education, Research and Care' has been established to coordinate the work of the programme. This work package covers generic issues that are relevant to all work packages. To this end, strategies are jointly devised, frameworks and conditions created and activities carried out to facilitate translation into practice and integration of research, healthcare and education, Open Science, registration and patient inclusion. For example, this work package can set out agreements on FAIR data and linking the work and results of the work packages. This also includes linking the results of the programme (and other programmes such as *Memorable!*) to the other two themes of the National Dementia Strategy. Applied research into the quality of life of people with dementia and their loved ones can also be carried out within the work package, as well as healthcare research to improve the organisation of care. One consortium will be formed that in any case involves all consortia leaders of the work packages 1, 2, 3 and 5; possibly supplemented by other parties (e.g. cooperation with Health-RI on FAIR data). This will contribute to the programme goal of strengthening and embedding the organisational, knowledge and data infrastructure for dementia research. Work package 6 is therefore also emphatically intended to help close the knowledge cycle. Various research disciplines and parties from healthcare and education will work together in the consortia. This will enable healthcare practice to feed the research with information, while the research can improve the care and the knowledge can be disseminated in education. Non-academic healthcare providers, such as healthcare institutions or primary care providers, can participate in the consortia and provide input for research programming. This will also be encouraged in the clinical fellowships.

### **3.3 National and international research and development**

The third goal of the Dementia Research Programme is to actively and meaningfully participate in international dementia research. Dementia affects the whole world. By cooperating internationally, we can undertake larger-scale research, share our data and pool research resources, so that breakthroughs come within reach more quickly. Dutch dementia research and care are highly regarded internationally, as is evident from the relatively high international profile of Dutch dementia research and the large number of successful applications of Dutch researchers as part of international partnerships.

The Dementia Research Programme aims to reinforce the prominent international role of Dutch dementia research and link it to international programmes by intensifying cooperation in dementia research.

The international context of dementia research is presented in Section 2 (Context of the programme), while Section 4 (Implementation of the programme) sets out the various action plans of the Dementia Research Programme in the international arena.

## 4 Implementation of the programme

The Dementia Research Programme focusses on contributing to solutions for dementia. This section describes how the programme is designed and implemented. The programme will run for ten years. The programming is based on a budget breakdown per grant instrument.

### 4.1 Grant instruments

The Dementia Research Programme deploys several grant instruments to implement the three programme goals. In addition to grant rounds for funding consortia, there is room for talent development (open fellowship rounds) and demand-driven rounds (for urgent research themes driven by policy goals or to forge links to other programmes).

Preliminary research can also be funded through the programme, e.g. pilot projects, feasibility studies and systematic reviews. These preliminary activities contribute to improving the relevance, quality and implementation of dementia projects. The deployment of these resources depends, among other things, on the type of research and the data already available.

Resources have been set aside for targeted dissemination and implementation projects to ensure the knowledge developed is usable and accessible and thus encourage its implementation.

#### 4.1.1 Funding the consortia

Cooperation and coordination promotes the transfer of knowledge between disciplines and ensures that the results can be translated into healthcare practice sooner. Cooperation between dementia researchers has increased in recent years, partly stimulated by *Memorabel*. This includes cooperation between organisations and between different disciplines. Dementia research under the umbrella of a multidisciplinary infrastructure can be more integrated and focused. To this end, ZonMw aims to invest a substantial amount of Dementia Research Programme funds in centres of excellence that are given room to carry out long-term programmes and establish and strengthen research partnerships. ZonMw aims to facilitate these centres and help them to develop into major players in their field and jointly build a leading national knowledge infrastructure for dementia research. The participation of private parties (funds and/or commercial) is permitted and will be encouraged in all work packages and consortia.

All consortia should reserve sufficient funds (preferably 3% of the grant) for Open Science and FAIR data management within the consortium.

The Dementia Research Programme aims to fund one or more multidisciplinary consortia in each of the six work packages. A detailed description and elaboration of the intended scope of the consortia will be set out in calls for grant applications for the relevant work packages.

#### 1. Fundamental Research

One or more consortia carrying out curiosity-driven research into the origins and mechanisms of dementia. This could include further identifying and improving our knowledge of the factors and mechanisms relating to genes, nerve cells, glial cells, proteins and neuroinflammation. The influence of blood pressure and damage to the brain caused by microbleeds could also be considered. The fundamental research has a link to the theme of risk reduction in the field of genetically informed prevention using treatments that are currently under development.

## 2. Risk Reduction

One or more consortia focusing on risk reduction in the general population. This could include input from the Netherlands Consortium of Dementia Cohorts<sup>6</sup> and results from lifestyle interventions (nutrition, exercise, social health). There may be links to the MOCIA study<sup>7</sup> and/or to various exposome studies. This work package should also link to the worldwide FINGER study<sup>8</sup>.

## 3. Diagnostics

One or more consortia working to improve the diagnosis and early diagnosis of dementia, preferably in cooperation with ABOARD. ZonMw will use the experiences gained with ABOARD for the implementation. The cooperation could extend to all forms of dementia, not just Alzheimer's disease.

## 4. Promising Innovative Therapies

Consortia that focus on therapeutic and technological interventions. These can include pharmaceutical treatments such as drug repurposing or research into new compounds, non-pharmaceutical treatments such as biotechnologies and medical technologies (for example deep brain stimulation) and healthcare interventions.

ZonMw aims to provide various consortia with funding to develop specific therapies in the form of multiple, smaller grant rounds (compared to the other work packages) during the ten years of the programme. The projects in these rounds will each run for approximately three years.

## 5. Early Onset Dementia

A consortium aimed at the target group of young people with dementia. This consortium will focus on specific fundamental and diagnostic knowledge of forms of dementia in young people, on individual patient research and also on the specialised personalised care that this group requires.

## 6. Knowledge Transfer: Integration of Education, Research and Care

A coordinating consortium that focuses on building an integrated infrastructure, frameworks and conditions, through which all consortia funded within the programme are linked. The repository for Open Science, translation into practice, upscaling and knowledge utilisation (including in education) can be organised within this consortium. Sufficient funds must be reserved for establishing the Open Science infrastructure.

Each consortium must comprise a network of strong research centres, one of which takes the leading role and already has its own line of expertise and research that is relevant to the research theme of the consortium. The Dementia Research Programme emphatically aims to involve all relevant stakeholders in each consortium. The five existing Alzheimer centres could be considered for the leading role, but other organisations could too.

### **Consortia grant rounds**

At the start of the Dementia Research Programme, a call for proposals will be issued for multidisciplinary consortia proposals for the work packages Fundamental Research (1), Risk Reduction (2), Diagnostics (3), Early Onset Dementia (5) and Coordination (6). The sandpit method may be used to form the consortia. The consortia in the work packages will initially be formed for four to five years, with the intention to extend this period by four years through a follow-up application. The consortia may also be integrated if required (under consideration). A consortium or work package can also cooperate with an applicant for a project under work package 4. Work package 4 has a different application route and duration, with several rounds of grants being organised.

This will be done in consultation with the programme committee on the basis of substantial arguments. It may be necessary to substantiate an application by means of a preliminary study (to determine the number of consortia per work package and precisely which resources are required). This will depend on the research goals, design and ambitions of the consortia. It is therefore not possible at this stage to determine with certainty how many consortia will be funded within each work package. This will be determined when the specific calls are opened. However, ZonMw will make cooperation between the consortia a condition as part of work package 6, and thus contribute to the goals of the National Dementia Strategy.

Table 1 at the end of this section provides an overview of the intended grant rounds. The amounts mentioned are only indicative and may vary in practice. It is unlikely that the resources will be equally distributed between

<sup>6</sup> <https://www.alzheimercentrum.nl/wetenschap/lopend-onderzoek/ncdc/>

<sup>7</sup> <https://www.wur.nl/nl/Onderzoek-Resultaten/Onderzoeksinstututen/food-biobased-research/Show-fbr/Leefstijlonderzoek-naar-behoud-van-optimale-cognitieve-functie-bij-veroudering-MOCIA.htm>

<sup>8</sup> <https://www.alz.org/wwfingers/overview.asp>

the themes, but the total amount for all the themes does give a good indication of the expected expenditure for all themes combined.

Criteria will be drawn up for monitoring the consortia (annual reports and progress interviews).

### **Composition of the consortia**

The composition of a consortium, and thus the number of cooperating organisations that jointly submit an application, may vary per application. This will depend on the context, goal and research question. It is important that the chosen consortium is clearly substantiated with a focus on result-oriented cooperation within the field of dementia research. The starting point is multidisciplinary and interdisciplinary cooperation, necessary for prioritising the research questions, the execution of the research and the implementation of the knowledge generated. The aim is to build consortia in which the biomedical and social domains can find common ground from the formulation of the research hypotheses onwards. One organisation will accept the role of consortium leader.

### **Research proposals**

Each consortium's research proposals must be realistic and coherent, but there is also room in the budget to follow research paths that may not have been fully fleshed out beforehand. However, all consortia are expected to formulate outcomes that address the objectives of the programme. These outcome measures will be further specified, depending on the type of research, with input from the programme committee (yet to be formed) and in coordination with the other themes of the National Dementia Strategy. Furthermore, the research proposals must address the intersecting themes of the National Dementia Strategy: Innovation, Communication and International.

Finally, the programme must promote an approach to the recognition and appreciation of researchers and their research that:

1. Encourages diversification of and more opportunities for career paths, thus promoting excellence in each of the core domains.
2. Does justice to both the independence and the individual qualities and ambitions of researchers, and to the achievements of the team.
3. Emphasises the quality of the work and places less emphasis on quantitative results (such as the number of publications).
4. Promotes all aspects of open science.
5. Encourages excellence in academic leadership.

The research proposals will be evaluated by the programme committee for relevance and against various quality criteria. For each work package, the Dementia Research Programme will determine the assessment criteria in consultation with the programme committee and, if applicable, in consultation with ZonMw programmes that have substantive expertise of the various themes (for example in the Fundamental Research, Prevention, LSH and Translational Research clusters).

### **Specification of work package 4**

As described above, the consortia within the Promising Innovative Therapies work package (4) will be formed through three grant rounds spread over the duration of the programme. These consortia will run for three to four years. The grant conditions in these rounds will be aimed at selecting and encouraging the most valuable high potential, groundbreaking innovations. The innovations can be in various phases of development. These consortia will focus on supervising the transfer of the innovations to the next phase and generating more impact (with an emphasis on the former). The consortia have, where relevant, a focus on the regional implementation of the outcomes. This regional focus is in line with the national strategy for, and organisation of, the new healthcare landscape and the strategic decision to focus on the regional level first. This regional approach also ties in with the regional infrastructure that is needed to scale up groundbreaking innovations. Finally, these implementing regions will also serve as a protective environment.

The consortia in work package 4 will thus be funded in several phases and in different stages of development. To this end, the programme will actively cooperate with Health~Holland and where relevant with RVO and InvestNL. The programme committee is responsible for targeted and integral portfolio management across the programme aimed at encouraging the various consortia to achieve the maximum output.

#### 4.1.2 Programming and funding talent development

In addition to funding large consortia, the Dementia Research Programme also aims to invest in individual research talents who can contribute to national dementia research. It is important to develop scientific talent to encourage the integration of Dutch dementia research in the international arena and facilitate an interdisciplinary approach. These funding pathways are especially intended for organisations that are not part of a consortium, to help them tie in their research with that of the consortia or to conduct promising dementia research. Fellowships are also available for professionals who will focus on healthcare research and improvements in working practice. A fellowship is an individual grant for a researcher whose work combines healthcare practice, education and scientific research. These grants can be made available at the start of the programme to link to the research themes of the Dementia Research Programme. They will complement the consortia funding at the start of the programme and ideally also create and/or strengthen links between the various consortia. Of course, talent development must also be encouraged within the consortia.

The fellowship grant rounds are intended to encourage research talent in the broadest sense. The performance of research or the number of publications are not the main goals of the funding. Other qualities, such as researchers who excel in teaching, translating results into practice and/or academic leadership will also be considered. ZonMw will apply the principles of ‘fair recognition and appreciation’<sup>9</sup> (as applied by NWO, KNAW, VSNU and others) to the Dementia Research Programme to ensure a broad range of talent is included.

In addition to its own fellowship grant rounds, opportunities for cooperation with the existing grant programmes for talent of ZonMw/NWO will be explored, such as the ‘Innovation Impulse’ and the ZonMw Open Competition, as well as Alzheimer Nederland’s fellowship grants. The programme will also continue to contribute to the ZonMw Off Road programme, which gives young researchers the opportunity to do pioneering, unconventional (and therefore scientifically potentially risky) research, i.e. *high-risk high-gain*.

The Dementia Research Programme will also join forces with other ZonMw programmes to look for opportunities for a joint educational programme. ZonMw will encourage network development by exchanging lessons learned and case studies.

#### 4.1.3 Programming and Funding through Targeted Rounds

##### Demand-driven rounds

Demand-driven research rounds enable the Ministry of Health, Welfare and Sport to put urgent research themes driven by policy goals on the agenda (possibly under the leadership of the steering committee of the National Dementia Strategy). This entails that the Dementia Research Programme will specifically describe the relevant theme and the research questions it involves at the request of the Ministry. It is also possible to provide a description of the research design in advance, on the basis of which a targeted call for research proposals is made.

The assessment criteria comprise quality and relevance criteria. The quality criteria are drawn up by the Dementia Research Programme and the relevance criteria by the programme in cooperation with the Ministry. If necessary, the evaluating programme committee will be supplemented with specific expertise required for the relevant call. This also provides an opportunity to link up with other dementia research programmes, such as an Off-Road grant round.

##### International cooperation on dementia research

The participation in the global Joint Programme on Neurodegenerative Diseases Research (JPND) will continue from 2021 under the auspices of the Dementia Research Programme. This is in line with the intersecting ‘International’ theme of the National Dementia Strategy and ZonMw’s policy to reserve about 10% of the programme budget for international collaborations to increase the effectiveness of grant funding. Since

<sup>9</sup> <https://www.zonmw.nl/nl/actueel/nieuws/detail/item/ruimte-voor-ieders-talent-naar-een-nieuwe-balans-in-erkennen-en-waarderen/>



2011, many Dutch researchers have been working successfully with JPND partners on solutions within the field of neurodegenerative research.

The following will apply to ensure the programme ties in with international developments:

1. The Dementia Research Programme participates in the JPND grant calls. In consultation with the programme committee it will be decided per round whether this affiliation is desirable or not. The procedures for grant rounds in JPND consortia are jointly determined together with the participating countries and established by the JPND Joint Call Secretariat.
2. ZonMw remains the lead organisation for the JPND monitoring and evaluation work package. In addition to pooling and further disseminating project results, activities will also be organised for researchers that facilitate the strengthening and expansion of their partnerships and collaborations to facilitate an even more efficient approach to research into neurodegenerative diseases and the development of new research initiatives.
3. Depending on the developments in Horizon Europe and EU4Health, participation in a follow-up to the JPND or other programmes from 2023, such as a possible partnership, will be considered.
4. Project applications made as part of the consortia and the projects must be in line with the international state-of-the-art. International cooperation is also important in order to share knowledge and experiences with other countries, as well as to deploy international knowledge for the benefit of Dutch healthcare practice. The consortia and the projects will also encourage researchers both young and old to work abroad for a period of time to gain work experience and to learn new methods and techniques. Researchers are required to allocate a budget for this talent development in their projects.

#### 4.1.4 Programming and funding through preliminary studies

The Dementia Research Programme can also programme and fund preparatory studies. Whether such a study is required will be decided in consultation with the programme committee. These studies could potentially be included in an existing grant round, for example by funding a proof of concept of a promising technique, whereby the larger follow-up project will only receive funding if the preliminary study is successful. A number of examples of possible preliminary studies are provided below.

- *Pilot studies*: Pilot studies can be used for breakthrough projects involving fundamental research or to optimise a research design in healthcare practice, whereby current healthcare practice and the preconditions for the study design are also taken into account. The pilot study can serve as a basis for further elaboration of the research and its design.
- *Feasibility studies*: A feasibility study is used to investigate whether a research proposal is feasible in daily practice. This could be in the form of a smaller-scale study conducted at a limited number of institutions. This study will provide an idea of the willingness of patients, clinicians and healthcare professionals to participate in the research.
- *Systematic review and meta-analysis*: Before a new clinical effectiveness study is started, it is important to systematically review what knowledge is already available. If no thorough systematic review or meta-analysis has been carried out, this can be funded as a preliminary study.
- *Cost effectiveness analysis*: It may be important to know to what extent the potential benefits of a study (health gains) outweigh the costs involved. A comparison of costs and benefits can provide more insight into the relevance of a particular study for implementation, as well as insight into the economic feasibility or potential of the returns. Applicants can apply for such funding (through a consortium or otherwise) to obtain additional support and expertise.
- *Methodological support*: Knowledge development and dissemination of appropriate research methodologies are also given due attention in the programme. This could involve the funding of methodological research questions in order to improve the quality of the research or its design. Applicants can apply for such funding (through a consortium or otherwise) to obtain additional support and expertise.
- *Promoting cooperation*: This grant is intended to facilitate new and existing cooperation between relevant parties in the design and implementation of the research, possibly as part of a consortium funding package. In addition to writing the project proposal, the funding can also be used to organise meetings

where relevant and concrete research questions can be fleshed out, or to establish partnerships and networks. For example, the funding can be used to organise round tables or platforms for sharing information between researchers. The *Memorabel* programme encouraged Dutch researchers to affiliate with the international network of the World Young Leaders in Dementia<sup>10</sup>, which has also led to new partnerships.

#### 4.1.5 Programming and funding through scale-up and implementation grants

The Dementia Research Programme has also reserved resources for scale-up and implementation grants. This includes grants for translational research, implementation and knowledge dissemination, e.g. for accelerating the development of high-impact innovations.

The impact of the knowledge generated by the consortia will be monitored and evaluated during the course of the programme. The grants for promising large-scale innovations can be increased if necessary.

#### 4.2.1 Overview of available funding for the work packages, research rounds and focus areas

Expenditure per grant instrument, total (indicative)			in € millions
WP: 1, 2, 3, 5, 6	Consortia*	2 rounds	62.5
WP: 4	Consortia*	3 rounds	22
Demand-driven rounds	Scope of/links to policy themes	Annual	12
International	JPND, follow-up	Annual	12
Preliminary studies	Miscellaneous	Annual	7
Fellowships	Individual	3 rounds	6
CIP - communication and implementation	All WPs and rounds		5, 2
Open Science	Programme-wide		2

Table 1

\*including reservation for open science in consortia

<sup>10</sup> <https://wyldementia.org/who-we-are/>

## 5 Target group participation

Participation is one of the policy spearheads of ZonMw. This section describes how the participation of the target group is embedded in the Dementia Research Programme.

### 5.1 Patient perspective and fundamental research

Target group participation can be relevant to any type of research, including fundamental research. It can help define research themes, such as in the development of treatments for symptoms and/or effects. Target group participation can be used to communicate the value and urgency of certain studies within established and valid areas of research. Clinicians and researchers need to be more aware of the value of involving people with dementia and their loved ones in the process of knowledge development and application. Various publications on this subject by ZonMw and other organisations can be found on the internet, including the Participation theme page on the ZonMw website<sup>11</sup> and the Participation Compass<sup>12</sup>.

### 5.2 Target Group Participation in the Dementia Research Programme

Participation of target groups is embedded in the Dementia Research Programme in the following ways.

#### Programme committee

One or more people who have dementia will sit on the programme committee to bring their perspective to the programme. These members will sit on the committee in a personal capacity. Alzheimer Nederland will be asked to recruit these members. These programme committee members with dementia will contribute to the discussion on the programme's strategy and have a voice in decision-making. The target group of Alzheimer Nederland will provide these committee members with input to help them when considering grant applications.

#### Assessment of research proposals and consortia

A strategy for target group participation will be determined depending on the type of research and the funding round. This will be agreed with Alzheimer Nederland in advance. For each round, the chosen approach will be elaborated and described in the call for proposals. For example, an independent panel consisting of people with dementia and/or informal carers could help assess the relevance of individual research proposals and the involvement of the target group. Researchers will be given the opportunity to respond to the panel's assessment and comments in a hearing and/or interview.

#### Participation within projects and consortia

The involvement of people with dementia and informal carers in the programme will contribute to the quality and practical relevance of the care and the research involved in it. The perspective of people with dementia and their networks should therefore also be included in research projects and within the consortia. Specific conditions will be drawn up to this end for each grant round, whereby the level of involvement of the target group will also be determined. This will also depend on whether there are human subjects involved in the research, or only animals. This requirement can then be implemented at the project or consortium level. A budget will also need to be reserved for this part of the application. This will make it possible to hire experts from Alzheimer Nederland for advice on target group participation, for example.

<sup>11</sup> <https://www.zonmw.nl/nl/over-zonmw/participatie/>

<sup>12</sup> <https://participatiekompas.nl/kickstart-voor-onderzoekers>

## ANNEX 1: ABBREVIATIONS

AAL	Active and Assisted Living
ABOARD	A Personalised Medicine Approach for Alzheimer's Disease
AI	Artificial Intelligence
ARRIVE	Animal Research: Reporting of In Vivo Experiments
BOOP	Policy, research, education and practice ( <i>Beleid, onderzoek, onderwijs en praktijk</i> )
CCMO	Central Committee on Research Involving Human Subjects
CIP	Communication and Implementation Plan
DPD	Dementia Delta Plan
EDA	Experimental Design Assistant
EVIR	Ensuring Value in Research
EZK	Ministry of Economic Affairs and Climate Policy
FAIR	Findable, Accessible, Interoperable, Reusable
FAST	Future Affordable and Sustainable Therapies
FINGER	Finnish intervention study to prevent cognitive decline and disability
GGG	Good use of drugs ( <i>Goed Gebruik Geneesmiddelen</i> )
GGZ	Mental health care service
HI-NL	Health Innovation Netherlands
HTA(i)	Health Technology Assessment (international)
IBI	International Brain Initiative
ICT	Information and Communication Technology
IVDR	In Vitro Diagnostic Medical Devices Regulation
JPND	Joint Programme - Neurodegenerative Disease Research
JZOJP	The right care in the right place ( <i>Juiste Zorg op de Juiste Plek</i> )
KIA	Knowledge and Innovation Agenda
KIC	Knowledge and Innovation Covenant
KNAW	Royal Netherlands Academy of Arts and Sciences
LSH	Life Sciences & Health
LZO	Long-term care and support ( <i>Langdurige Zorg en Ondersteuning</i> )
MedTech	Medical Technology
MDR	Medical Devices Regulation
METC	Medical Ethics Review Committee
MOCIA	Maintaining Optimal Cognitive function In Ageing
NFU	Netherlands Federation of University Medical Centers
NWA	National Research Agenda
NWO	Dutch Research Council
PET	Positron Emission Tomography
PPP	Public-Private Partnership
PREPARE	Planning Research and Experimental Procedures on Animals: Recommendations for Excellence
RCT	Randomised Controlled Trial
RIVM	National Institute for Public Health and the Environment
SMART	Specific, Measurable, Acceptable, Realistic, Time-bound
STZ	Association of Tertiary Medical Teaching Hospitals
TKI	Top consortia for Knowledge and Innovation
TRL	Technology Readiness Levels
UMC	University Medical Center
VSNU	Association of Universities in the Netherlands
VWS	Ministry of Health, Welfare and Sport
WHO	World Health Organization
ZN	Association of Dutch Healthcare Insurers