

# National Research Strategy on Dementia 2025



Research for the benefit of people with  
dementia and their relatives

## **National Research Strategy on Dementia 2025**

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**ISBN online:** 978-87-7014-113-0

**Language:** English

**Version:** 1st edition

**Versions Date:** 28.06.2019

**Format:** pdf

Published by Danish Health Authority,  
December 2018

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# 1. Preface

This national research strategy for the benefit of people with dementia and their relatives stems from 'A Safe and Dignified Life with Dementia – National Action Plan on Dementia 2025', which focuses on improving the standard of knowledge and competency.<sup>1</sup> The Action Plan on Dementia earmarked DKK 6.7 million to strengthen dementia research. These resources will be spent on five industrial PhD students who will conduct research on dementia and on drawing up the 'National Research Strategy on Dementia 2025 – research for the benefit of people with dementia and their relatives'.

This research strategy is primarily intended for researchers and decision-makers with an interest in strategic considerations about prioritisation of research efforts in the field of dementia and adjacent fields. Thus, the aim is to set the direction for research in dementia up to 2025, leading to improved dementia care at municipal, regional and national levels as well as improvements to efforts arising from organisations and civil society. It is essential that dementia research reaches across fields of expertise and sectors. However, there must also be room for focused research that goes into depth in a specific area.

The research strategy also supports the three main national objectives of the National Action Plan on Dementia 2025.

## National goals for dementia care 2025

1. Denmark's 98 municipalities must be dementia-friendly
2. More people with dementia must be assessed and 80% must have a specific diagnosis
3. Better care and treatment must result in a 50% reduction in the use of anti-psychotics in people with dementia by 2025

The work on the research strategy is conducted by the Danish Health Authority with the involvement of the Danish Dementia Research Centre, the Danish Agency for Science and Higher Education and a number of other relevant stakeholders in an experts' group (see Appendix 2).

<sup>1</sup> A Safe and Dignified Life with Dementia – National Action Plan on Dementia 2025', Danish Ministry of Health, January 2017.

At the end of 2017, the Danish Health Authority invited the universities, university colleges and relevant organisations to appoint delegates to an experts' group with broad representation, covering the perspectives of researchers, users, recipients and funding.

The experts' group met a total of four times during 2018. In the course of the process, a smaller writing group was selected from the experts' group to formulate a draft research strategy in collaboration with the Danish Health Authority. The experts' group subsequently contributed by formulating, commenting on and underpinning the final research strategy for dementia.

All contributors hope that this strategy will be able to inspire regions, municipalities, universities and other research environments to prioritise dementia research within the scope defined by the strategy.

Many thanks to all who contributed to and were involved in the work on the research strategy.



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## 2. Introduction

Dementia is a condition that turns life as we know it upside down. Consequently, it does not only affect the sufferer but has an impact on the whole family and those close to them. Dementia is also a condition for which we have no effective treatment, and which challenges both our health service and society as a whole.

More knowledge is essential if we are to improve dementia efforts for the benefit of people with dementia and their relatives. Research can give us a better insight into questions such as how to prevent dementia, which interventions work when someone develops a dementia disorder and how knowledge and skills can be put into practice to ensure that family and healthcare professionals derive greater benefit from the latest knowledge in the field.

The purpose of this national research strategy is to support dementia efforts by research across fields of expertise and sectors for the benefit of people with dementia and their families. The aim of the research is to ensure that there is relevant, research-based knowledge about methods and endeavours for prevention, treatment, care and psychosocial interventions in the fields of health and social care. In addition, research must clarify how effective methods will be implemented as well as the costs associated with implementation.<sup>2</sup>

<sup>2</sup> Wording of Initiative 19 of the National Action Plan on Dementia 2025. Danish Ministry of Health.

### 3. Challenges of dementia

Dementia is the name given to impairment of mental capacity due to disease in the brain. There are more than 200 diseases which can lead to dementia. Some are extremely rare whereas others are more prevalent. Alzheimer's disease and vascular dementia account for almost eight out of ten cases of dementia in the elderly (over the age of 65). The distribution is somewhat different in younger people with dementia; only about 50% of all cases are due to Alzheimer's disease, vascular dementia and mixed dementia whereas other causes are relatively more prevalent, including frontotemporal dementia.<sup>3</sup>

The main presenting feature of dementia is impairment of cognitive function, e.g. memory problems which reduce ability to perform everyday tasks. People with severe dementia are completely dependent on the help of others, 24 hours a day. On the other hand, those with milder dementia are often able to manage with a little support from those around them.

Dementia is the most frequent reason for assessments for residential care and is registered as the fifth most common cause of death in Denmark. There are not yet any medications to cure dementia disorders. However, the right medicinal and psychosocial care can improve the quality of life for people with dementia and their closest relatives during the course of the illness. The hope is to identify an effective cure or medication to slow the progression of the disease so that dementia becomes less debilitating in the future. Regardless of the progress on the medical front, it will be crucial – for the individual dementia sufferer, their family and society as a whole – to investigate the potential for, and to identify, effective, health-promoting and preventive measures so that a smaller proportion of the population develops dementia in the future.

The most recent population projection expects the population in Denmark to grow up to 2060 and primarily the very oldest age group to increase in size.<sup>4</sup> According to the National Patient Registry, a certain proportion of the population over the age of 65 will develop dementia. In 2016, around 36,000 elderly people (over the age of 65) in Denmark had been diagnosed with dementia.<sup>5</sup>

The number of younger people, under the age of 65, with a dementia disorder was approximately 3,000. However, this figure is subject to uncertainty.<sup>6</sup> Many people live with

<sup>3</sup> Prince M, Knapp M, Guerchet M et al. (2014) Dementia UK: Update. London: Alzheimer's Society.

<sup>4</sup> Statistics Denmark, <https://www.dst.dk/da/Statistik/nyt/NytHtml?cid=26827>

<sup>5</sup> Figures are based on the number of people over the age of 65 who were registered in the National Patient Registry or the Danish Psychiatric Central Research Register as having a dementia diagnosis in 2016 (as a primary or secondary diagnosis), or who had filled a prescription for dementia medicine registered in the Register of Medicinal Products Statistics. As of 1 January /2016, 36,000 people ≥65 were registered as having dementia in Denmark. Dementia must be registered from the age of 60.

<sup>6</sup> Figures are based on an annual average from 2010 to 2012 (2,977 people under the age of 65), according to this publication: Flachs EM, Eriksen L, Koch MB, Ryd JT, Dibba E, Skov-Ettrup L, et al. National Institute of Public Health, University of Southern Denmark. Burden of disease in Denmark – diseases. Copenhagen: Danish Health Authority, 2015.



dementia without ever being assessed and diagnosed. It is therefore relevant to examine the estimated number of people with dementia. Based on thorough Danish and international population studies previously conducted, the Danish Dementia Research Centre estimated that 89,985 people had dementia in Denmark in 2018. This figure is expected to increase significantly in the coming years as the population gets older.<sup>7</sup> It was estimated that, worldwide, almost 47 million people had dementia in 2015. This is expected to increase to 131.5 million by 2050.<sup>8</sup>

The direct healthcare and social costs associated with dementia are estimated at approximately DKK 10 billion annually.<sup>9</sup> The estimates are based on cost data supplied by a number of municipalities in the Capital Region of Denmark, converted to a national average. However, if the calculation is derived from estimates of prevalence of dementia based on population studies, and an assumed 'hidden number' of old people with undiagnosed dementia is added, the cost estimate increases significantly. In addition to the costs mentioned above, indirect costs associated with relatives' loss of earnings must be added to gain a complete picture of cost to society. In Denmark, this cost is estimated at just below DKK 7.4 billion.<sup>10</sup> To this must be added the extra cost of treatment by the patient's own GP and at hospital as well as the cost of increase in relatives' ill-health. Thus, dementia is already a great challenge for both the health service and society as a whole, and it is expected to grow in line with the increasing number of people with dementia.

Partly due to demographic changes, with an aging population, it is already a challenge to find qualified experts to care for the increasing numbers of people with dementia. In many cases, relatives see to care in the home. This is a significant burden and increases the risk of both mental and physical disorders in relatives. The growing numbers of people with dementia result in a greater need to identify solutions to ensure that these people can remain in their own homes and retain and use their own resources for as long as possible. The solutions must help people with dementia feel included in society and retain their dignity and independence while receiving the help and support they need. During the course of the disease, sufferers will lose their autonomy and legal capacity, and this gives rise to numerous ethical and legal challenges which must be addressed.

Finally, it poses a challenge that many cases of dementia are not detected and assessed. There may be many reasons for the lack of, or late, diagnosis. One of these may be a feeling that diagnosis is useless since there is no effective treatment. Another reason may be a lack of awareness in the person's network of the early signs of dementia.

There are several reasons for the uncertainty attached to the number of people with dementia, including the fact that some were only diagnosed by a general practitioner and, therefore, do not figure in the National Patient Registry. In addition, many people with dementia are never examined and, therefore, have not received a diagnosis.

<sup>7</sup> The estimate for 2018 is based on calculations by the Danish Dementia Research Centre of the number of persons over the age of 60 with dementia.

<sup>8</sup> Prince M, Wimo A, Guerchet M, et al. (2015). World Alzheimer Report 2015. The global impact of dementia. London: Alzheimer's Disease International.

<sup>9</sup> Danish Dementia Research Centre: The cost of dementia. Link: <http://www.videnscenterfordemens.dk/statistik/omkostninger-forbundet-med-demens/>

<sup>10</sup> Danish Dementia Research Centre: The cost of dementia. Link: <http://www.videnscenterfordemens.dk/statistik/omkostninger-forbundet-med-demens/>

Lack of information in society about dementia may lead to misunderstandings about symptoms and contribute to taboo and stigma. This may prevent some people from reacting to symptoms. As a result, many people are not diagnosed and do not receive optimal help and treatment, which can have serious human and health consequences for people with dementia and their relatives.

Dementia is therefore both a great personal challenge for those with the disease and their relatives and a challenge for the health service and society as a whole. The aim of the research strategy is to be a long-term strategy to stimulate dementia research in Denmark by setting a clear direction for research priorities, based on current Danish research strengths.

## 4. Starting point and aim of the research strategy

The national research strategy is based on Danish research strengths with particular potential relevance for dementia research. In addition, international initiatives such as other countries' research strategies on dementia have provided inspiration for the work to develop the Danish strategy. Based on Danish research strengths and international trends, the Danish national research strategy for dementia sets a direction for future Danish research, including a range of strategic indicators to lend the research quality and ensure added value.

### 4.1. Danish research strengths

The RESEARCH2025 catalogue (2017) introduces tomorrow's strategic research areas and provides a summary of Danish research's current positions of strength. In the field of healthcare, in particular, Denmark has a number of unique strengths in basic biomedical research, biology of pathogens as well as registry and bioinformatics research. The fact that researchers have easy access to data registries, biobanks and the upcoming National Genome Centre gives research in Denmark unique potential.<sup>11</sup> Denmark is also known for its relatively high level of IT readiness in the population and a high degree of mutual trust between population and authorities, which among other things can form the basis for implementation of research-based initiatives. Furthermore, Denmark has biotech, life science and health technology industries which are very involved in research, including dementia research. In conclusion, Danish health research is characterised by a high proportion of funding from private foundations and organisations and by its high scientific impact.<sup>12</sup>

Several of these general conditions in Denmark can also be utilised in the context of dementia research. Furthermore, as part of the development of the research strategy, a range of Danish strengths are described as having particular potential relevance for dementia research.<sup>13</sup>

<sup>11</sup> 'RESEARCH2025 – promising future research areas.' Danish Agency for Science and Higher Education, 2017.

<sup>12</sup> Research Barometer 2018 – Annual statistics and analysis of research and Innovation. <https://ufm.dk/publikationer/2018/filer/forskningsbarometer-2018.pdf>

<sup>13</sup> 'Dementia research – proposal for a research strategy', prepared by Implement Consulting Group for the Danish Health Authority, 2018.

Strength	Potential
A welfare system with extensive health and social services, professionally trained staff and well-developed voluntary organisations	Denmark has a nationwide welfare system, covering the entire population. Everyone has the same rights and receives reasonably uniform offers. This provides potential for large cross-municipality and cross-sectorial projects. Employees are ensured basic professional training, and the overall interdisciplinary/professional standard in practice can be useful in research and development partnerships. Furthermore, a well-developed voluntary sector has knowledge and networks which can be useful in research contexts.
National health data, registries, databases and biobanks	These data sources provide particularly good conditions for identifying correlations when using big data and artificial intelligence, for identifying predictors in large sections of the population and for following cohorts over time.
Research environments with high impact and volume, a high level of skill and good cooperative relations with the private sector	Denmark already has strong dementia research environments and networks. There are also several budding research environments, partnerships and networks with potential for enhancement. In addition, there are numerous strong research environments in related fields, such as molecular biology research and diagnostic imaging, which currently only deal with dementia research to a limited extent but which have potential in the long term to contribute to the field.
Private enterprises in the fields of life science, biotech and health technology	Denmark has several research-intensive companies working in the field of neurodegenerative diseases which already contribute to dementia research in general and which have potential to develop new, effective therapies and technological solutions for dementia disorders.
High level of IT readiness in the population	IT readiness and the excellent IT skills of the population can be used for data collection and increase willingness to use digital solutions with the potential to assist with the daily challenges of dementia.
The population's interest in participation in research	Intervention research can benefit from the high degree of mutual trust which enables patients and members of the public to participate in dementia-related research projects.
Meeting point for knowledge creation and sharing	It is considered a strength that there is already a national meeting point, the Danish Dementia Research Centre, which can help strengthen research environments and exploit knowledge by entering into research partnerships. In addition, there are research environments and professional networks which prevail across university colleges, health and social sciences and humanities with the potential to enter into national and international collaboration on dementia research.

Danish research must make use of the strengths which give us unique opportunities to conduct research of an international standard. Dementia is not merely a challenge for Danish society; it must be seen in a wider global context. Many countries are facing the same demographic development and, thus, the same health challenges. Furthermore, some of the great advances in prevention, and particularly in finding a cure for dementia, are identified in international research partnerships. Consequently, we must consider Danish dementia research in an international context.

#### 4.2. International Initiatives

At a European level, dementia has been referred to as one of our greatest social challenges. Therefore, in 2012, the member states established a collaboration on research into neurodegenerative disorders, Joint Programming on Neurodegenerative Disorders (JPND).<sup>14</sup> Since 2014, the health programme under the EU Framework Programme for Research and Innovation, Horizon 2020, has funded almost 30 projects – worth a total of EUR 150 million – within the EU in the field of neurodegenerative diseases, including Alzheimer's disease and dementia.<sup>15</sup> Another important international player focusing on dementia is the public-private partnership between the EU Commission and the pharmaceutical industry in Europe, Innovative Medicines Initiative 2 (IMI2). One of IMI2's most important focus areas is Alzheimer's disease. Since 2014, it has supported 14 major projects relevant to Alzheimer's research, including a budget of almost EUR 60 million for the European Prevention of Alzheimer's Dementia Consortium (EPAD), with Denmark as one of the participants.

In JPND's 2018 mapping exercise report, it is estimated that public and private foundations in Denmark (2016) give EUR 6.8 million each year to research in neurodegenerative diseases. The great majority of these funds go to basic research, although only a small proportion goes to dementia research.<sup>16</sup> In recent years, other countries have launched national research strategies accompanied by large public or public-private investments, e.g. the UK, the Netherlands and Norway, and several countries are in the process of developing strategies.<sup>17</sup> JPND's research and innovation strategy for dementia and some of the national research strategies provided a source of inspiration for the work to develop a Danish research strategy for dementia.

<sup>14</sup> 'Strategic Research Agenda 2012', JPND, 2012, and 'Research and Innovation Strategy 2018', JPND, 2018.

<sup>15</sup> Under the auspices of the Horizon 2020 health programme, Societal Challenge 1, Health, demographic change and wellbeing.

<sup>16</sup> 'JPND Mapping Exercise Report', 2018, JPND Research, 2018.

<sup>17</sup> Memorabel (Netherlands) <https://www.zonmw.nl/en/research-and-results/the-elderly/programmas/programme-detail/memorabel/>

UK Dementia Research Institute (England) <https://ukdri.ac.uk/vision>

Dementia Plan 2020 (Norway) <https://www.regjeringen.no/no/dokumenter/demensplan-2020/id2465117/>

At a global level, WHO drew attention to dementia in 2017 with its 'Global action plan on the public health response to dementia 2017-2025'.<sup>18</sup> Prior to drawing up this global action plan, WHO asked researchers from all over the world to identify and prioritise the most important research needs for the field of dementia.<sup>19</sup> The study showed that some of the top priorities were development of new methods for prevention and reduction of the risk of dementia, new and effective therapies and better quality of support and care. The global action plan lists a range of initiatives for realising the vision of a world in which dementia can be prevented and people with dementia and their relatives receive the care and support they need to live a life with meaning and dignity. Areas for action also include research and innovation with a target to double the output of global research on dementia between 2017 and 2025. This could be achieved, for instance, by increasing investment in dementia research and developing, implementing and monitoring national research strategies. Many countries, including Denmark, have signed up to WHO's goals for dementia care.

WHO's work on dementia includes the launch of an initiative to follow up on a range of key parameters, including indicators for data collection and research related to efforts to improve the lives of those with dementia in all countries of the world.<sup>20</sup> The Global Dementia Observatory Indicator Dictionary includes topics such as whether there is a national research strategy and plan, how this is implemented, the extent of public funding for the plan, the number of people with dementia included in research trials, and how these are incorporated into research planning. Denmark participates in the second wave of implementation, which was initiated in 2018.

<sup>18</sup> 'Global action plan on the public health response to dementia 2017–2025', WHO, 2017.

<sup>19</sup> Shah H, Albanese E, Duggan C et al. (2016) Research priorities to reduce the global burden of dementia by 2025. *The Lancet Neurology*, 15(12), 1285-1294.

<sup>20</sup> 'The Global Dementia Observatory', WHO, 2018.

## 5. Strategic indicators

Based on the Danish research strengths and international trends, collaboration and obligations, the national research strategy for dementia defines four indicators for Danish dementia research. These indicators can give the research quality and add value.

### **Four strategic indicators for tomorrow's dementia research in Denmark**

- **Involvement of users and research for the benefit of all**
- **Research of the highest international standard and international collaboration**
- **Improved use of data and technologies**
- **Translation of research into innovation and knowledge into benefit**

#### **5.1. Involvement of users and research for the benefit of all**

To add the greatest possible value to dementia research, users should play a significant role in the research process. This is to ensure that the research conducted is relevant and topical. It is therefore a high priority that people with dementia and their relatives are involved in prioritisation, planning, implementation and communication of research efforts.<sup>21</sup>

#### **5.2. Research of the highest international standard and international collaboration**

Danish dementia research must be of a high international standard in order to attract funding by Danish and foreign grants which are open to competition. For this reason, Danish research and research partnerships must be able to profit from the Danish positions of strength. In addition, it must be possible to strengthen budding and new research environments that have potential, since multidisciplinary research can bring new and innovative solutions to the field of dementia. Finally, Danish and international partnerships and networks between researchers and research institutions should be developed and supported.

<sup>21</sup> Gove D, Diaz-Ponce A, Georges J et al. (2018) Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). *Aging & Mental Health*, 22:6, 723-729.

The borderland between research and innovation must be stimulated, preferably across scientific disciplines and within a public-private partnership including Danish biotech, pharmaceutical and technological enterprises.

### **5.3. Improved use of data and technologies**

Widespread access to national health data, registries, databases and biobanks in Denmark provides unique opportunities for identifying correlations when using big data and artificial intelligence, for identifying predictors in large sections of the population and for following cohorts over time. Initiative 21 of the Action Plan on Dementia involves further development of the Danish Clinical Quality Database for Dementia with a view to strengthening the data base for dementia.

Creating free access to scientific articles and research data can help research institutions improve the efficiency of research by reuse of data. This can promote interdisciplinary research, which can add great value for researchers, members of the public and enterprises by providing new knowledge and discoveries.

Therefore, where relevant, research can benefit from the unique Danish registry data and, to the extent possible, provide free access to research results and data. Furthermore, research can benefit from incorporating technology and digitisation where relevant, and can contribute to development of the great potential of this field.

### **5.4. Translation of research into innovation and knowledge into benefit**

Multidisciplinary, cross-sectorial and interdisciplinary research should contribute to stimulation of innovation and evidence-based practice in dementia care at regional and municipal levels. In this way, research can help ensure that there is relevant research-based knowledge about methods and endeavours for prevention, treatment and care as well as psychosocial interventions in the fields of health and social care for the benefit of people with dementia and their relatives. Furthermore, research could produce knowledge about how to implement methods most cost-effectively for the benefit of people with dementia and their families. Knowledge should also be made available to all relevant educational institutions through communication and translation of the latest research-based knowledge. Strong research and knowledge environments at universities, university colleges and business academies may help support this.



## 6. Recommendations for research

There are a number of research efforts that should be prioritised if we, in Denmark, are to meet the many challenges associated with dementia disorders. It is, for instance, vital for research to focus on prevention and on identifying effective, new therapies for dementia disorders as well as ways of compensating for functional impairment caused by dementia if we are to be prepared for the anticipated increase in the number of dementia sufferers and affected relatives and, thus, an increasing need for high-cost care. In the short term, however, it is also essential to fund research which, above all, serves to improve an evidence-based approach to efforts for people with dementia and their relatives in municipalities and regions. This includes prevention, treatment and care and well as psychosocial interventions in the fields of health and social care. Consequently, the strategy focuses on the needs of people who currently suffer from dementia and their relatives as well as the needs of those in the future.

The experts' group has defined a range of more specific recommendations for research efforts to meet the human and societal challenges of dementia. With four prioritised themes, the research strategy sets a direction for assessing where research funds can be of greatest benefit for people with dementia, their relatives and society as a whole. In addition, the four indicators (cf. Chapter 5) establish a common approach for research to meet challenges, benefit from the Danish positions of strength and meet Denmark's international obligations.

### The four themes of the research strategy

Based on concrete research needs and existing international research strategies, the future strategy for Danish dementia research is summarised in four themes

- A. Causes and mechanisms of the disease**
- B. Assessment**
- C. Prevention, treatment and psychosocial intervention**
- D. Support, care, well-being and society**

To differing degrees, the four themes of the research strategy address the challenges relevant to people with dementia both now and in the future. Thus, some of the recommendations will be relevant to people already living with dementia, whereas other research efforts will only benefit people with dementia in the future.

The theme-based breakdown adheres to international trends and terminology. For example, it is closely aligned with the themes used in the Dutch dementia research strategy – Memorabel – and, to a large extent, JPND’s strategy. This makes the strategy more comparable and communicable in cases where translations may be difficult. The targeted thematisation of the research ensures that work can be based on different goals within the same specialist fields. However, the themes are not mutually exclusive. Some points overlap, since much of the latest research will be relevant to more than one theme.

### 6.1. Causes and mechanisms of the disease (A)

Genes, environmental impact and lifestyle factors all contribute to the biological development of dementia disorders. However, we still do not know how these factors produce dementia. Knowledge of the disease mechanisms is key to prevention, diagnosis and treatment of dementia disorders and a condition for identifying a cure for dementia.

#### Causes and mechanisms of the disease

Research should identify the underlying causes and mechanisms of dementia disorders by:

- A.1** examining how cardiovascular mechanisms, lifestyle factors, environmental and psychosocial factors, mental disorders and other diseases affect the risk of developing dementia, both on their own and in combination with genetic risk factors. This knowledge is usually produced by major, meticulous population studies.
- A.2** examining molecular disease mechanisms in patients who have developed hereditary forms of dementia and investigating small groups of healthy people and people in the early stages of dementia where the correlation between risk factors, cognition and brain pathology is identified through genetic and epi-genetic studies, brain scans, neuro-psychological studies and other studies of brain function.
- A.3** new molecular and cell-based systems and animal models of changes which reflect mechanisms of dementia disorders in people.

#### 6.1.1. Objectives

Further knowledge about the precise changes that occur in the brain at a cellular level will contribute to our knowledge of the disease mechanisms behind development of a de-

mentia disorder. This knowledge is important in terms of improving prevention and treatment of dementia disorders. It is also essential to the work to identify a cure for dementia (A.2 and A.3). Furthermore, it is important to know more about a range of risk factors and how they affect the risk of dementia so that we can become far more effective at preventing and treating dementia disorders (A.1).

## 6.2. Assessment (B)

The diagnostic methods available to us today are not sufficiently precise during the early stages of dementia. As a result, a precise diagnosis is often not made early enough. For a variety of reasons, a large proportion of people with dementia are never assessed or diagnosed.

### Assessment

Research in connection with this theme should focus on:

#### Detection

- B.1** development and validation of clinical assessment tools for the primary sector which are able to identify people at increased risk of dementia and improve potential for referring those who show signs of dementia for assessment.
- B.2** technological solutions which, to an increasing degree, are used for diagnostic purposes. It is vital that these technological solutions and their implementation are evaluated and evidence-based.

#### Precise diagnosis

- B.3** development of new, easily accessible and less invasive predictors as well as cognitive tests and clinical assessment scales which can detect the specific dementia disorders in their early stages.
- B.4** methods for definition of the phases of the specific dementia disorders to create potential for more effective and personalised medical therapies and other interventions.

- B.5** development, harmonisation and validation of diagnostic procedures across cultures, age and gender, regional and professional stakeholders to ensure consistent quality and a high diagnostic standard.

#### **Significance of the diagnosis**

- B.6** understanding of the ethical, healthcare, social and psychological significance of early diagnosis through research on related topics such as quality of life, prevention, burden on relatives and the economy.

#### **6.2.1. Objectives**

Together with new cognitive tests, development of new clinical tools and technological solutions can improve the quality of assessment and ensure more timely and precise diagnosis (B.1, B.2, B.3, B.4 and B.5). This also ensures more relevant treatment and other offers (cf. themes C and D) by providing people with dementia and their relatives with information and advice. Early intervention is key to supporting quality of life and level of function, preventing or reducing deterioration as much as possible and promoting general health. Precise diagnostic methods are also important because some patients who are assessed due to cognitive symptoms do not actually suffer from a dementia disorder but from something else and should therefore be offered a different, more relevant treatment.

It is life-changing to be told that you suffer from a dementia disorder. Increased knowledge and understanding of the ethical, social and psychological significance of early diagnosis can help ensure that people with dementia and their relatives receive the right offers (B.6). This knowledge can also help promote discussion of the ethical implications of early diagnosis and detection.

#### **6.3. Prevention, treatment and psychosocial intervention (C)**

Dementia has a range of risk factors which are modifiable. Research is required to identify how we best prevent further symptoms and reduction of level of function once a dementia disorder has developed. There is also a need for research to elucidate how medical treatment, psychosocial intervention including rehabilitation, innovative technologies and other interventions can lower the risk of developing dementia. People with dementia often also have many concurrent disorders, which individually and in combination affect the overall condition and prognosis, and which complicate both medical treatment and other interventions.

## Prevention, treatment and psychosocial intervention

Research in connection with the theme of prevention, treatment and psychosocial intervention should focus on:

- C.1** effective prevention of dementia based on greater understanding of the causes and mechanisms of the disease (cf. theme 1), e.g. in the form of multi-domain interventions which could include lifestyle changes, treatment of disease and strengthening of physical and cognitive resources.
- C.2** effective treatment of dementia based on greater understanding of the causes and mechanisms of the disease (cf. theme 1), in the form of both development of new medicines and pharmacological intervention studies.
- C.3** development, implementation and evaluation of the effect of psychosocial interventions, i.e. methods with the purpose of supporting, developing and retaining the psychological, cognitive, functional and social resources of people with dementia for as long as possible and maintaining quality of life, dignity and comfort for the individual. This also includes methods that involve their relatives and strengthen their resources.
- C.4** psychosocial interventions, which also include rehabilitation, and research on rehabilitation should focus on establishing an understanding of the mechanisms and potential for rehabilitation of people with dementia throughout the entire course of the disease, i.e. rehabilitation interventions to reduce deterioration and maintain physical and cognitive function as much as possible.
- C.5** research into how to maintain or improve level of function and quality of life in people with dementia and other physical or mental illnesses (co-morbidity) by means of better psychosocial interventions and healthcare therapies, and how these initiatives can be implemented and coordinated effectively across sectors.
- C.6** development and validation of new outcome measures for medical and psychosocial interventions which can be applied to all phases of the disease, including in relation to prevention or very early treatment of dementia disorders.

### 6.3.1. Objectives

More knowledge about how best to organise, undertake and implement treatment and psychosocial interventions, including rehabilitation, may improve the quality of prevention and therapies.

When we know more about the effect of meeting individual needs in interventions, we can increase opportunities for the person with dementia and their relatives to live independently, meaningfully and with dignity despite the disease (C.1, C.3, C.4 and C.5).

Development of new outcome measures, which are robust and involve quality of life and physical, cognitive and social function, and which also reflect the targets set for the specific initiative, may help to measure the effect of therapies and interventions in people with dementia (C.2, C.5 and C.6).

Research can increase knowledge and evidence which can support initiatives at municipal, regional and national levels as well as initiatives within the framework of organisations and society as a whole in relation to prevention, treatment and psychosocial intervention (C.1, C.2, C.3, C.4 and C.5).

## 6.4. Support, care, well-being and society (D)

Cross-sectorial and multidisciplinary research on initiatives for people with dementia and their relatives is important in order to be able to support regions and municipalities in their efforts to organise their general approach in the best possible way. It is essential that research involves people with dementia and their relatives in order to ensure that their needs and preferences are met and that methods promote well-being and quality of life, counteract social isolation and promote a dementia-friendly society.

There is a need to gain a greater insight, in general, into how it is to live with dementia, both for the actual sufferer and for their relatives. This will enable us to organise initiatives better but also to eliminate the stigma and prejudices about the disease.

In spite of a strong focus on skills development over the past few years, there is still a need to gain a better understanding about how to translate knowledge into practice and about what happens in the interaction between healthcare professionals and people with dementia and their relatives.

Technologies for dementia care are in rapid growth, both everyday technology aimed at the individual with dementia or intended to support the resources and needs of relatives and technology used by professionals in their work with activities for and care of people with dementia. These technological tools and their implementation should, in the same way as other interventions, be underpinned by research and evidence.

It is important that implementation and organisation of initiatives are elucidated in research. Similarly, there should be focus on the health economic aspects of the initiatives. Finally, a range of key ethical and legal factors must be addressed in the research.

## **Support, care, well-being and society**

Research in connection with the theme of support, care, well-being and society should focus on:

- D.1** increased knowledge about the dementia-friendly society and how it can be made operational and implemented. It is also relevant to identify how we ensure equality of access and good transitions between systems in relation to initiatives and offers.
- D.2** increased understanding of needs, preferences and perspectives of people who live with dementia and their relatives and how these perspectives can be incorporated into political, research and other societal aspects concerning dementia.
- D.3** development, implementation and organisation of methods for advising and supporting people with dementia and relatives and of approaches and methods for care in all phases of the disease, including coordination of palliative and rehabilitation initiatives.
- D.4** development and implementation of technology for dementia care and research into the effects of such technology.
- D.5** health economic aspects, including research into the most cost-effective methods for implementation of therapies and interventions.
- D.6** identification of the many and multi-faceted ethical aspects and legal issues in the field of dementia, for instance in relation to legal capacity and how these issues are handled and implemented in relevant contexts in order to ensure that the human rights of people with dementia are secured and that they can live safe and dignified lives.

- D.7** new methods for training and competence development of healthcare professionals to prepare them for interaction and collaboration with people with dementia and their relatives.
- D.8** continued development of methods for person-focused care, including psychosocial care initiatives which contribute to well-being, dignity, quality of life and meaningful daily life for people with dementia and their relatives.

#### 6.4.1. Objectives

A larger shared knowledge base about, for instance, advice and support for people with dementia and their relatives – which care, rehabilitation and palliative initiatives work and why – can help ensure greater consistency across municipalities and sectors (D.2 and D.3) of offers for families when they are affected by dementia. It is also essential to know how these methods and approaches can best be implemented and, based on this knowledge, to develop new methods for training and competence development of healthcare professionals (D.3 and D.7).

Similarly, the rapid development of technological tools and their implementation should be underpinned by research and evidence in order to ensure that investments are made where they do the greatest good and produce the greatest gain in terms of ensuring that people with dementia and their relatives can live independent, safe and dignified lives (D.4 and D.5).

A better, humanistic insight into how it feels to have dementia or be a relative of or carer for a person with dementia can help provide a broader and more nuanced understanding of dementia as a phenomenon (D.1 and D.2).

Many municipalities and organisations have launched initiatives working towards a dementia-friendly Denmark. However, we know very little about what we can do to promote this dementia-friendly society and how to make it happen. Consequently, there is a need for more qualified and specific knowledge about what makes a society dementia-friendly (D.1, D.2, D.6 and D.7).



## 7. Framework for the research

In December 2017, the Danish government launched its strategy for Danish research and innovation. This sets ambitious targets for Danish research to continue to be of the highest international standard and for the research to provide the greatest possible benefit to society. This national research strategy for dementia has earmarked the research fields that will be of greatest benefit to people with dementia and their relatives based on the challenges we are currently facing, but also those we will face in the future.

The experts' group suggests that the research strategy has a greater chance of realisation if a framework is established to enable continual monitoring of the effect of the research strategy and adjustment of the strategy, if needed, in order to align it with actual needs for knowledge and development in the field of dementia. WHO recommends, among other things, that member states monitor realisation of the national research strategies. In line with this, the Netherlands has established a board in partnership with a number of public and private stakeholders to support and monitor implementation of the national research strategy. Similarly, when complying with this strategy, it will be essential to strengthen the framework and foundation for research for the benefit of people with dementia and their relatives.

Danish research on dementia must be able to be used in international cooperative initiatives and must be of the highest standard. This has already been selected as one of the four indicators for this strategy. Dementia research cuts across many research fields and traditions. Dementia research and knowledge about dementia are therefore rooted in many different research and development environments at universities, hospitals, university colleges and business academies. Some are well-established and are part of international networks, others are up-and-coming with little or no international collaboration. We already have outstanding Danish research in the field of dementia, and there is potential for even more researchers and research environments to contribute to global knowledge creation.

In order to achieve the goal to conduct dementia research of a high international standard, a range of frameworks and terms must be in place.

### 7.1. Strengthening research environments

The basis for conducting outstanding research is availability of well-established research environments with strong national and international working relationships, where people can learn from each other and gain inspiration. Bringing in additional experienced researchers with skills and experience of an international standard, particularly to the budding research environments, can help generate volume and quality in projects and ensure the next generation of researchers by providing young researchers with supervision.

Potential for multidisciplinary and international collaboration and opportunities for participating in international, including European, research partnerships can help improve the academic standard and provide new knowledge. This can also be achieved by attracting foreign researchers to Danish research institutions and by collaborating on doctoral studies across Europe. An action plan has been drawn up as an element of Denmark's political strategy for research and innovation. This plan includes initiatives associated with the EU Framework Programme for Research and Innovation, Horizon 2020, which aim to strengthen Danish participation in EU research and innovation, doctoral studies and mobility of researchers.

It must be possible to retain talented and able researchers. This is most achievable if there are attractive working conditions and clear career paths. Attractive working conditions do not merely provide access to research funding, they also lead to good opportunities for being included in strong national and international research environments. This could also involve access to physical facilities and infrastructures and, for example, potential for cooperating with practice and access to data and technology. The Danish Council for Research and Innovation Policy (DFiR) is in the process of preparing a report on careers in research. This will form the basis for further efforts to create even better conditions for talented researchers.<sup>22</sup>

With the political strategy for research and innovation – 'Denmark - Ready to seize future opportunities' – the Danish government proposes strengthening the research talent programme Sapere Aude Research Leader and the national ERC (European Research Council) funding scheme. In the agreement on distribution of research reserves in 2019, DKK 55 million is earmarked for expansion of the research talent programme Sapere Aude Research Leader and for continuation of the national ERC funding scheme, with up to DKK 10 million specifically for the national ERC funding scheme. This is a contribution to continuation of the work to support tomorrow's leading researchers. The aim of the funding for Sapere Aude Research Leader is to support particularly talented young researchers who are ready to develop and strengthen their own research ideas and to run a research project with several participants of a high international standard. At the same time, continuation of the national ERC funding scheme is intended to boost the potential for talented young researchers to receive ERC grants for excellent and ground-breaking research based on the researchers' own ideas in all research fields.

Furthermore, partnerships between public and private stakeholders can often help consolidate innovation processes, while contributing investments, knowledge, knowhow and access to technologies which can make the research environments more attractive.

<sup>22</sup> 'Denmark - Ready to seize future opportunities. The Government's objectives for Danish research and innovation', Danish Ministry of Higher Education and Science, 2017.

## Recommendations for strengthening research environments

Based on the above, the recommendations are to:

- strengthen the framework for multidisciplinary and international collaboration with both formal and informal forms of cooperation.
- increase focus on clear and attractive career paths for researchers.
- strengthen collaboration between more established research and development environments and budding research and development environments.
- strengthen partnerships between public and private stakeholders

## 7.2. Strengthening research infrastructure

High quality research depends on a research infrastructure that provides, for example, access to databases, sophisticated equipment, laboratory facilities and practice as well as opportunities for involving users in research projects.

Access to health data registries has already been mentioned several times as a particular Danish strength, which gives research unique potential. However, there is still a need to secure better cross-sectorial registry data. Standardised methods, platforms and tools for data collection and analysis, including use of artificial intelligence for analysis of big data, can also help strengthen research.

It is assessed that there is significant potential in further promoting researchers' access to practice. Ensuring better access to people with dementia through systematic cooperation with municipalities can help generate the project volume necessary to achieve conclusive outcomes. At the same time, optimised access to research-based knowledge can help translate research into practice, where it is relevant. More systematic collaboration between sectors and development of research skills at regional and municipal levels can help strengthen collaboration with practice, ensuring user involvement and employee perspectives in research contexts.

## Recommendations for strengthening research infrastructure

Based on the above, the recommendations are to:

- boost the quality of data and include and develop new data for use in the field of dementia, including municipal data.
- increase opportunities for researchers to gain access to practice and user involvement, for instance through closer and systematic cooperation between research and development environments, municipalities, regions and organisations.

### 7.3. Supporting stable financial frameworks

Stable conditions, including reliable and adequate funding, are necessary for research to provide answers and solutions to the great challenges facing humanity and society due to dementia. No specific funding has been earmarked for research to realise this strategy. Consequently, focus is directed towards identifying ways in which dementia research can claim its share of research funding through the usual channels. The experts' group also points out that implementation of the strategy will be strengthened by investing more specifically in dementia research with a view to enabling Denmark to contribute to international goals to increase production of knowledge on dementia (cf. WHO's Global Target 7: 'The output of global research on dementia doubles between 2017 and 2025').

The Danish government maintains an annual allocation of at least 1% of gross domestic product (GDP) to research and development. At the same time, funding given to research by private foundations is on the increase, which provides potential for additional activities in the field of dementia research. While some foundations aim to take on a more active role in certain areas of dementia research, some research fields find it a challenge to obtain funding from foundations.

On a larger scale, it is particularly relevant to address ways for Danish dementia research environments to obtain the greatest possible share of European research funding in the future. This funding is primarily tied to the EU's seven-year framework programmes for research and innovation (today 'Horizon 2020', and from 2021 onwards 'Horizon Europe'), including affiliated public-private partnerships such as IMI2 and public-public partnerships such as JPND. There is strong competition among researchers to gain a share of the funding provided for international dementia research. This helps ensure that the best research projects are given funding. Danish researchers should have the best conditions and skills for participating in these application processes. On the whole, Denmark receives a large proportion of the funding from the Horizon 2020 programme today. However, it is important to continue working to provide Danish researchers with the incentives, support, knowledge and skills required to seek the research opportunities offered by the EU. This requires ongoing focus on coordinating efforts between local research funding units and the EuroCentre at the Danish Agency for Science and Higher Education.

#### Recommendations for supporting stable financial frameworks

Based on the above, the recommendations are to:

- promote potential for public and private stakeholders to co-finance research activities.
- enhance skills for applying to foundations through existing offers and by strengthening research management and necessary support functions.

## 8. List of references

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## 9. Appendices

### 9.1. Appendix 1: Explanation of terms

This text uses a range of terms which can be difficult to define clearly – particularly when the strategy is as broad as this one. Concepts such as prevention, assessment, detection, early intervention, treatment, care and rehabilitation can have different meanings depending on academic perspective and research tradition.

It can also be difficult to give a name to the people this strategy concerns – people with dementia and their relatives. In one context, they will be patients, in another they will be members of the public and in yet another they will be residents in a care facility. We have chosen to call them people with dementia or dementia sufferers.

Unless otherwise stated, this explanation of terms is based on OECD definitions.

Term	Definition
Applied research	Experimental or theoretical work primarily aimed at specific application areas.
Basic research	Experimental or theoretical work with the primary objective of acquiring knowledge and understanding without any specific application in mind.
Big data	In this document, 'big data' refers to data quantified based on a number of dimensions (the four Vs): <i>Volume</i> : scale of data; <i>Velocity</i> : how fast data increase, e.g. online data; <i>Variety</i> : content of different forms of data; and <i>Veracity</i> : degree of uncertainty of data. Data must have a high value in more than one category in order to comply with the definition 'big data'. Follow the link for further details: <a href="https://www.ibmbigdatahub.com/in-fographic/four-vs-big-data">https://www.ibmbigdatahub.com/in-fographic/four-vs-big-data</a>
Development	Development is systematic work based on knowledge acquired through research and practical experience, with the purpose of producing new or significantly improved materials, products, processes, systems or services.

Innovation	Innovation refers to implementation of a new or significantly improved product (or service), process or method. Innovations may be based on new knowledge and technology but can also be combinations of – or new applications for – existing knowledge and technologies.
Rehabilitation	<p>In this document, rehabilitation falls under the general umbrella term 'psychosocial interventions'.</p> <p>WHO defines rehabilitation as a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments.</p> <p>Source: 'World Report on Disability, 2011', World Health Organization &amp; The World Bank, 2011</p> <p>There are many other ways of interpreting the concept of rehabilitation and its practice. In a Danish context, the White Paper on the Concept of Rehabilitation is also used as an overall designation of bio-psycho-social measures aimed at people living with dementia.</p> <p>Source: 'White Paper on the Concept of Rehabilitation', MarselisborgCentre, 2004</p>
Relatives	<p>Relatives are referred to in this document as people in family with those with dementia as well as people who do not necessarily have any family connection, including closest friends, acquaintances, neighbours and fellow patients. Consequently, it is always the individual with dementia who decides who his/her closest relatives are.</p> <p>Source: 'Recommendations for healthcare professionals in their interaction with relatives of the seriously ill', Danish Health Authority, 2012</p>
Psychosocial interventions	<p>Psychosocial intervention is an umbrella term for initiatives aimed at supporting, developing and retaining the psychological, cognitive, functional and social resources of people with dementia and/or their relatives. In this document, rehabilitation falls under the general umbrella term 'psychosocial interventions'.</p> <p>Source: Moniz-Cook E, Vernooij-Dassen M, Woods B et al. (2011) and Moniz-Cook E, Vernooij-Dassen M, Woods R et al. (2008)</p>



## User involvement

In this document, user involvement in research contexts refers to involvement of patients (people with dementia) and relatives. There are two levels of user involvement: individual and organisational.

Individual user involvement refers to the patient's and relatives' involvement in their own process. In the case of organisational user involvement, users are representatives of the user's perspective in processes of significance for organisation, development and evaluation.

In the case of involvement of relatives, a distinction is made between relatives as a resource during care and treatment of the person with dementia and relatives' own need for support.

Source: ViBIS: <https://danskepatienter.dk/vibis/om-brugerinddragelse/definition-af-brugerinddragelse>

Healthcare professionals are recipients of the new knowledge, methods and technologies and, therefore, may be included as users in some research contexts.

## 9.2. Appendix 2: Composition of the experts' group

The research strategy is drawn up by the Danish Health Authority with the involvement of the Danish Dementia Research Centre, the Danish Agency for Science and Higher Education and a number of other relevant stakeholders in an experts' group.

The experts' group met a total of four times during 2018. The aim of the first two meetings was for members to gain a broad overview of significant research activities and environments and to collect research requirements from key stakeholders, including regions and municipalities, educational institutions, research, knowledge and innovation environments and user representatives. In parallel with this, Implement Consulting Group prepared a report for the Danish Health Authority which, based on the meetings, a number of interviews and document reviews, gave an overview of Danish research activities, topics and partnerships in the field of dementia and outlined potential strategic research prospects.

A smaller writing group was subsequently selected from the experts' group to formulate a draft research strategy in collaboration with the Danish Health Authority. In the following two meetings, the experts' group contributed by formulating, commenting on and underpinning the final research strategy for dementia.

Background material is available in the list of references.

### Members of the experts' group

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