

## The Statement of the Translation

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This statement is to certify that the presented translation from Norwegian into English is correct. In addition, we certify it is a word-for-word translation of the document's original language. The original document is issued in Norwegian and has been awarded to our client, Norwegian Brain Council.

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Strategi

# National Brain Health Strategy (2018-2024)







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## The smart device

It is with you everywhere you go. It's with in the morning when you're trying to get out the door with the kids, in the afternoon when you cut your finger chopping onions in the kitchen, and in the evening when you stumble towards the bedroom a little too late.

It keep tracks of work and leisure, reminds you of meetings to be held and reports to be written. It remembers the little one's training times and the housing cooperative's notice about voluntary work.

It helps you to do your job. It helps you to keep track of your body. It helps you live. It remembers the ones most dearest to you. What you love the most.

I am not referring to a smartphone. I am talking about something far more complex and far more advanced. I am referring to your brain. The device that is smarter than the most intelligent smartphone.

When the brain is affected by disease or injury, a lot is affected. Getting the kids off to school in the morning and cooking dinner in the afternoon goes from normal to an oddity. Keeping up with to-do lists with important meetings and your little one's training timetable becomes impossible.

It might be difficult to do your job. It might be difficult to keep track of your body. It might affect your loved ones and what you love the most. It can change your life. It can shorten your life.

Therefore, we need a brain health strategy on how to best prevent disease and injury, and how to best investigate and treat them. How we can best help patients and their families to cope with disease and injuries that affect the brain.

A smartphone can be used for many things, even if it has cracks in the screen and takes a long time to recharge. This applies to the brain as well. Although the smart device might change, it can still be used for many things, for example, living.



**Bent Høie**  
Minister of Health and Care Services  
12th December 2017

## Incredible brain

Billions of nerve cells continually send signals via small and large networks. The brain is the most complex known structure in the universe. As an irreplaceable organ, it makes us who we are. Therefore, it is essential to take good care of your brain.

Like any other organ, the brain is affected by disease. This can range from an acute disease or injury with sequelae to congenital or acquired chronic diseases.

Over 30 per cent of the population will be affected. Brain diseases are the most common cause of disability and the second most common cause of death.

Brain diseases cause half of the diseases that place a burden on society.

If we look at brain diseases as a whole, we understand the actual extent of the situation, and it also becomes more transparent that the health services have under-prioritised brain health for a long time. It is a paradox that Norway has only just recently started to use the term 'brain health'.

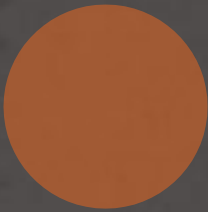
Brain diseases affect a wide range of people in all stages of life. It could be an acute condition with a high risk of mortality or a condition that causes the affected to live with a brain disease for a large portion of their life.

Society benefits hugely from preventing brain diseases and improving the health services for those affected. Active and equal participation from users is vital to create better brain health within the population.

Prevention of brain diseases, good and equal treatment, follow-up and rehabilitation, as well as increased research and expertise, is a good social investment and an investment in the individual.



**Henrik Peersen**  
Chairman of the Norwegian Brain Council





# Introduction

At a summit in March 2017 addressing brain diseases, i.e. amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), dementia, Huntington's disease and Parkinson's disease, Prime Minister Erna Solberg and the Minister of Health and Care Services, Bent Høie, announced that a national strategy for brain health would be created to develop better services. The Norwegian Directorate of Health, the Norwegian Brain Council, professional environments and users arranged the summit after the joint submission of a brain health status report.

Brain health is a new concept in Norway. *The National Brain Health Strategy (2018-2024)* shall set the course for prevention measures, and guide the health and care services, and research. The strategy shall include objectives and point out how the objectives can be achieved. It also forms a basis for political choices and initiatives. The Norwegian Ministry of Health and Care Services has created the strategy with the input of the Norwegian Directorate of Health, the Norwegian Brain Council and a number of professional environments and users.

The strategy mainly concerns the responsibility of the municipal and specialist health services. Good brain health depends on prevention and the promotion of health, early intervention, diagnosis, treatment, habilitation, rehabilitation, and research and innovation. It also concerns the elevation of each individual's ability to focus on their own brain health and to control his/her life with impaired functionality caused by a brain disease.

The strategy has four overarching objectives:

## **1. Good lifelong brain health, prevention and quality of life**

The strategy shall increase the awareness of the population of the most crucial aspects of good brain health from conception to death. In some cases the risk of developing a brain disease can be reduced by a healthy lifestyle. A healthy lifestyle can help improve one's quality of life despite having a disease. The strategy shall highlight the importance of healthy choices for good brain health through government campaigns and information. Learning and coping services can help improve a person's ability to cope with living with a brain disease.

## **2. Health and care services that are more user-centred and take better care of relatives**

Patients and relatives are a resource for the health and care services, and their experiences shall be actively used to improve services. The aim is to develop patient engagement tools for patients with a brain disease to enable them to actively participate in decisions related to diagnosis, treatment, and monitoring. ParkinsonNet is a model that enables patients to come into contact with networks that have multidisciplinary expertise in close proximity to their homes, based on what the patient knows about his/her disease and treatment. The goal is to develop more networks based on experiences with ParkinsonNet. Relatives are an invaluable resource to their loved ones, as well as to society. Therefore, one of the objectives is to secure good follow-up and guidance for relatives.





### **3. Good care from the onset of symptoms to diagnosis, treatment, habilitation and rehabilitation**

Patients with a brain disease require a holistic course of treatment. A more team-based service might give a more multidisciplinary and coordinated service. Experiences from cerebral stroke treatment packages, mental health and substance abuse should be used to safeguard good care for more patients with brain disease.

Learning Network gives municipalities access to expertise and knowledge they do not possess themselves. The aim is to increase the use of learning networks to enable municipalities to better engage in skills development and change processes.

### **4. Adequate knowledge and quality through research and innovation**

The Government is asking the Norwegian Research Council to announce the allocation of NOK 20 million for the establishment of new research centre scheme for clinical treatment. Initially, the announcement will concern the establishment of a clinical research centre for serious diseases of the central nervous system, such as amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS) and dementia. The Government realises that Norwegian brain research environments need to cooperate with domestic and global networks to find out why the diseases develop, how they can be treated and how patients can best live with the disease or impaired functionality, etc. In addition, the Norwegian Research Council will be strengthened with an additional NOK 5 million.

### **Why have a strategy for brain health?**

We do not know enough about the causes of brain diseases. Many of the conditions indicate the need for comprehensive assistance and follow-up through adapted services, and patients rely on both municipal and hospital services. Good care and treatment requires close cooperation between these entities. This could be particularly relevant in the long-term, sometimes lifelong, rehabilitation phase.

The Norwegian Directorate of Health's Brain Health Status Report (2017) shows that cooperation between the different levels of treatment varies. Unequal access to expertise prevails, and users want to be assured that the services intercommunicate to provide coordinated

services.

Patients with chronic diseases, who require multiple and complex services often need the same from the health and care services. Diseases such as dementia, cerebral strokes and mental health disorders are addressed in separate plans or governmental strategies. Other areas will be reviewed in upcoming reports on services offered to children with brain damage, autism and similar diagnoses, etc. Chapter 7 provides an overview of closely related work/strategies.

The brain health strategy does not address specific treatment or measures aimed at individual diagnoses. The strategy does, however, follow-up feedback from professionals and patient organisations about some disease groups that have not received special mention in earlier Governmental initiatives. Neurodegenerative disorders, such as MS, ALS and various chronic pain conditions will thus have a place in this strategy.

### **Brain Health and brain diseases**

Brain health is an overarching term that encompasses everything from initiatives designed to maintain and develop a healthy brain to brain diseases and injuries. Brain health expresses a health condition related to functionality, diseases, injuries and disorders of the brain and other parts of the nervous system (Norwegian Directorate of Health, 2017). The definition includes psychiatric and neurological diseases and disorders, injuries and dependency disorders. This complies with the global interpretation of the term brain health (Norwegian Directorate of Health, 2017). The term brain health provides new perspectives on diseases that affect the masses. One in three Norwegians are affected by a brain disease during their lifetime.

When preparing the Norwegian Directorate of Health's Status Report, it could not be agreed which mental health disorders to include in the term brain health. Neuropsychiatric and psychological disorders in which biological factors are assumed to be a key factor are included in the brain health strategy.

A particular challenge for patients with brain disease is that the disease can result in reduced cognitive function and some patients will experience personality changes. This is often challenging for both patients and their relatives.

The Norwegian Directorate of Health contributed to the work on the strategy with a proposal to divide the diseases and disorders into three groups. The division forms the basis for the brain health strategy:

- Acute disorders: includes acute diseases, such as cerebral strokes and acute injury after, for example, an accident, medical treatment or during birth.
- Progressive disorders: includes diseases of the nervous system that undergo gradual or periodic/intermittent deterioration, such as MS, Parkinson's disease, Huntington's disease, ALS and various dementia diagnoses.
- Chronic disorders: includes long-term disorders, that sometimes consistently recur or lifelong conditions. Such disorders might include some serious mental disorders, psychoses and primary headache disorders.

After the Norwegian Directorate of Health's assessment, it was found that such grouping of disorders might be particularly significant in helping the health and care services to understand the challenges faced by patients and relatives, and how to approach patients with different brain diseases. This especially applies to the municipal multidisciplinary services, which include: healthcare services, day care, support measures and respite care at home, etc. The three groups can also overlap. Progressive disorders are also chronic and some acute disorders can overlap with chronic disorders.

### How can good brain health be promoted?

Good brain health is promoted where people live their lives - at home, school, in the workplace and during leisure. Psychosocial factors that enable patients to cope and give them quality of life are important to brain health in the broadest sense of the term.

Health promotion and prevention measures must be enforced in all sectors - not just in the health and care services.

Children and adults with brain diseases depend on an adapted daily life. It might be a difficult task for relatives, but the work they do is crucial to ensure a good life for patients with a brain disease or brain damage. Schemes for financial compensation for reduced income, practical

measures at home and respite care can be just as important as help from the health and care services.

Education is essential for securing the future opportunities of children and youths. Employment is vital to many people, as it gives them a social life and enables them to contribute to society. Schools and employment, municipal and governmental support schemes and services, in addition to the help of the voluntary services, are very important to the lives of many people with a brain disease or injury.

Good brain health initiatives for the health and care services include information about prevention, diagnosis, diagnostics, treatment, habilitation, rehabilitation, research and innovation.

### Implementing and following up the strategy

The Norwegian Ministry of Health and Care Services must specify and implement the various objectives and sub-objectives of the strategy within their areas of responsibility and financial constraints. In some areas, it might be appropriate to reallocate resources.



## Primary and sub-objectives of the strategy

### 1. Good lifelong brain health, prevention and quality of life

- The population shall become more educated about the important aspects of good brain health and quality of life from conception to death.
- The health authorities shall highlight the importance of healthy choices for good brain health through information and campaigns.
- The local authorities, through cooperation with user organisations, the private sector and non-governmental organisations, shall develop more quality-assured services to promote a healthy life, learning and coping skills.
- Health promotion and prevention work will be increased throughout the health and care services.

### 2. Health and care services that are more user-centred and take better care of relatives

- The aim is to develop patient engagement tools for patients with a brain disease to enable them to actively participate in decisions about diagnosis, treatment, and follow-up.
- Patients are actively involved in the preparation of quality-assured health information regarding diseases and coping strategies.
- A broad professional network should be established, which unlike the model on ParkinsonNet, should not be limited to diagnoses.
- Services, activities and respite care is adapted to each patient/user
- Relatives and children as the grieving relative receive proper follow-up and guidance.

### 3. Good care from the onset of symptoms to diagnosis, habilitation and rehabilitation

- Leaders of the municipal health and care services and specialist health service must follow-up routines for the coordination of services for users with complex needs.
- Municipal health and care services and the specialist health service must have good routines for the life cycle transition from adolescence to adulthood.
- Create interdisciplinary and coordinated services based on the patient's wants and needs.
- Team-based services within the municipality shall be developed based on the user's needs and functional ability.
- Patients in need of habilitation and rehabilitation will be offered such services in their own municipality.
- Hospital outpatient services shall support municipal services to care for users who live in their own home
- Implement national treatment

programmes for children who have acquired a brain injury.

- Ensure that patients and users with a long-term need for coordinated services exercise their entitlement to an individual plan and coordinator.
- The Norwegian Directorate of Health follows up and evaluates initiatives in the Dementia Plan 2020, the utilisation of adapted home care, systematic follow-up after diagnosis and daily activity services.
- Increase the utilisation of the measures in the Dementia Plan 2020 to cover more target groups.
- Consider developing a common course of treatment for groups of brain disease patients with similar functional impairments and monitoring requirements.
- Develop the offer of treatment for children with brain damage through regional health authority initiatives and optional treatment.
- Maintain treatment programmes overseas for children and young people with brain damage until the regional health authorities can offer different healthcare in Norway
- More health personnel within the municipal health and care services shall use learning networks.

### 4. Adequate knowledge and quality through research and innovation

- The Government has asked the Norwegian Research Council to announce the allocation of NOK 20 million for a clinical research centre, as a multiyear effort devoted to severe diseases affecting the central nervous system, for example, ALS, MS and dementia. In addition, the Norwegian Research Council will be strengthened with an additional NOK 5 million.
- The experiences of users and their need for information will form the basis for improved quality, research and innovation.
- The Government will facilitate the development, testing and documentation of new solutions in cooperation with the public health and care services, and the private sector.
- Develop several national quality indicators, especially indicators for treatment outcomes.
- Help ensure that the competence of graduates corresponds to a greater degree to the services and needs of users, and that a national standard of education is developed through the introduction of a new system for steering the learning outcomes of foundation-level health and social education programmes at universities and university colleges.
- Cooperate by exchanging e-learning lesson plans and health service simulation experiences.

# 2



## A changing and developing society

From now up until 2030, Norway will undergo massive societal changes. Developments in the population, the age structure of the population, a changed pattern of diseases, new technology and people's expectations of quality, treatment options and standards, will greatly impact the development of the health and care services. Patients and relatives want a more central role in the monitoring of their disease, and self-care training and coping skills will be a vital element of all monitoring.

### More elderly people

Statistics Norway estimates that the population will reach 5.9 million by 2030. This figure is not accurate, but some developments are quite certain. For example, the increased number of elderly will lead to a rise in the demand for health and care services. In addition, the *National Health and Hospital Plan* (Meld. St. 11 (2015-2016)) states that in 2030 there will be about 300,000 more people over the age of 70 than today, which is more than a 50 per cent increase. Thereafter, both the number and percentage of elderly people will steadily rise. The age structure of the future population will probably lead to a rise in the number of people affected by a cerebral stroke, dementia and Parkinson's disease.

It may seem that the elderly have more diseases now, but it also seems that they live with their diseases better than before.

This could be due to the improvement of medical care, physical environment and technology enabling the elderly to cope on their own. Furthermore, the elderly are more educated today. (Statistics Norway, 2017).

### Diseases within the population have changed

The health and care services must adapt to the needs of the population and future disease patterns. The white paper on *primary healthcare* (Meld. St. 26 (2014-2015)) states that the disease pattern will primarily be characterised by an aging population and more people will live with a chronic disease for a portion of their lives. The Norwegian Directorate of Health's Status Report (2017) provides an overview of a variety of brain diseases and prevalence.

Disease burden estimates provide information on how various diseases, injuries and risk factors affect people in the form of 'non-fatal health outcomes' and mortality measured as 'years of potential life lost'. Years of potential life lost is an estimate of the average years a person would have lived at the time of death, whilst non-fatal health outcomes are calculated based on the prevalence and severity of the disease. Non-fatal health outcomes and years of life lost are summarised to attain the 'quality adjusted life year'. Estimation of the disease burden aims to provide a comprehensive overview of the health status of a population.

The Norwegian Institute of Public Health's report on the disease burden in Norway (2017), provides an overview of the state of health of the Norwegian population and the distribution of disease, death and risk factors.

The report shows that:

- Cardiovascular diseases, cancer and neurological diseases (mainly dementia) are the main cause of death.
- Going into more detail, the main causes of death are: ischemic heart disease (mainly heart attacks); dementia; cerebrovascular disease (cerebral stroke); COPD; and lung cancer. The first four diseases tend to occur in old age.
- Mental disorders and musculoskeletal diseases are responsible for most years lost due to health outcomes in Norway.

Alzheimer's and other forms of dementia cover an important group in terms of lost years of life and non-fatal health outcomes. Migraine headaches are a high disease burden in terms of non-fatal health outcomes. Cerebral strokes account for a large proportion of quality-adjusted life years in the population.

Even though cerebral strokes are still a frequent cause of death in Norway, the mortality rate has fallen considerably the last 30 years. This is largely due to the organisation of treatment in stroke units and improved treatment. A thrombectomy (blood clot fishing), as soon as possible after the onset of symptoms of a major heart attack has proven to be highly effective in the long-term.

## New technology and people's expectations

The progression of medical technology has enabled more people to live longer and cope with a disease in their lives. Many will need monitoring for the rest of their lives. The demand for health and care services is continually rising and, in most cases, treatment is getting more expensive. Through new technology and innovative services, less labour-intensive services can be offered, whilst freeing up the time of health personnel. The *National Health and Hospital Plan* (Meld. St. 11 (2015-2016)) states that the demand and expectations of the public when it comes to the health and care services could escalate in line with income rises, and knowledge and standard of living within the population in general.

Medical equipment, welfare technology and assistive devices can, in many cases, help people with health outcomes to live in their own homes longer and to actively participate in society. The rise in the number of people under the age of 67 is greater than indicated by the population growth. This means that more people will require home care in the future.

## Insufficient knowledge

In many areas, we do not possess enough knowledge about the prevalence or causes of brain disease nor effective treatment that can slow down or cure the disease. Our knowledge about the effects of measures on treatment and the organisation of services varies (Directorate of Health, 2017). Furthermore, there are no good mechanisms in place to ensure that research findings and new innovations are distributed or implemented as new information within the services.

Excellent health and quality registries are available to record prevalence and courses of treatment. Data from the registers can be used for research and quality development to see the effect of measures or changes in the population over time. These registries should be quality assured and utilised to a greater extent than today. The Municipal Patient and User Registry, which is currently being established, along with the Norwegian Patient Registry, Norwegian Prescription Database and National Medical Quality Registry provide good base data for the monitoring of patient care and division of health and care services according to disease, age and geographical groups.

The Government is investigating the establishment of a prescription registry that will identify patients based on drug-usage data from hospitals, nursing homes and the Norwegian Prescription Database, see the white paper on *public health, coping and opportunities* (Meld. St. 19 (2014–2015)). The Norwegian Parliament has endorsed this. The Norwegian Ministry of Health and Care Services has commissioned the Norwegian Institute of Public Health to assess the need for technical changes and to find out which data sources shall form the basis for the registry

## Geographical variation

The Norwegian Directorate of Health's Status Report (2017) describes the geographical differences regarding diagnosis, treatment and monitoring of individual groups, for example, those with a cerebral stroke, autism, ADHD and progressive diseases and disorders. The difference is probably due to different diagnostic practices, different organisation of the services and non-standardisation of diagnosis procedures and treatment of the conditions. The status report also indicates that the cooperation between the somatic health service and the mental health service might have failed.

## More municipal responsibility

The municipalities have been given more responsibility in that some tasks and responsibilities of the specialist health service have been transferred to the municipalities. In addition, the length of time spent in hospital has been reduced. The Government has presented its *Habilitation and Rehabilitation Escalation Plan* (Prop. 1S (2016-2017)) in which one of the key objectives is that the municipalities shall gradually adopt some of the tasks of the specialist health service. The Norwegian Directorate of Health's Status Report (2017) refers to insufficiencies within habilitation and rehabilitation in both the municipal and specialist health services in terms of capacity, expertise and interaction between the various tiers.

Patients with a brain disease also need specialised rehabilitation. The capacity and competence of the hospitals offering rehabilitation for brain diseases varies.

People with a brain disease need coordinated services, good patient care and multidisciplinary services within a lifelong perspective. Monitoring of patients with chronic neurological disorders often requires close and continual cooperation between the patient's GP, other municipal services and the specialist health service. A significant number of patients and users find that the services are fragmented with limited availability. Many have the right to an individual plan and coordinator, but do not receive one. The status report also shows that special challenges prevail in connection with the transition from childhood to adulthood in habilitation services.

Insufficient competence within public services for people with functional impairments is a continual challenge. The status report also shows that some diseases and disorders are rare and that treatment has become so advanced that it can be difficult for the doctor and other medical personnel to meet the updated competence requirements.

Those who have a known disease and are waiting for further follow-up in hospital, do not always receive adequate attention. It is important to follow the patient up through the patient's entire course of treatment. This is why treatment packages for brain cancer were introduced in 2015. Treatment packages will be introduced for cerebral stroke patients, mental health disorders and substance abuse disorders in 2017 and 2018. A new indicator for exceeding the planned length of hospitalisation periods was also introduced in 2017. It measures delayed patient contact.

## Coping and user interaction

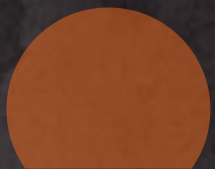
Municipalities and hospitals weight user participation in different ways in connection with individual treatment, monitoring and the design of the services offered.

Technological developments enable patients to play a more central role in the monitoring of their own illness. Training in the administration of medications, self-care and the competence to assess whether one should seek the help of the health services is becoming increasingly important. Several hospitals and municipalities offer educational and coping courses to introduce patients to some basic diagnoses and disease monitoring. This is a coping service that helps patients to become more confident in caring for themselves, and it is sought by more and more patient groups.

Preventive low threshold and coping services are important to increase the patient's self-coping skills and to prevent further functional impairment. Figures from KOSTRA (Municipal-State-Reporting) show that 260 municipalities had established so-called healthy living centres by the end of 2016. This service helps to improve the patient's quality of life through lifestyle changes. One of the goals is that more municipalities will either independently or through intermunicipal cooperation establish healthy living services for their citizens.







# 3



## Objective 1: Good lifelong brain health, prevention and quality of life

Health, learning to cope and quality of life are all interrelated.

In *the white paper, Coping and Opportunities*, (Meld. St. 19 (2014-2015)) one of the overarching objectives is that "the population shall experience many years of good health and well-being." The concepts of well-being and quality of life are often used interchangeably, but both relate to the things that make life worth living, fill up life and give it meaning, in addition to how a good life can be facilitated, even with impaired health. The Norwegian Directorate of Health's *Good Life in Norway Report* (2016) uses a broad understanding of the term in order to measuring quality of life. Further work may lead to better understanding and insight into the concept of quality of life and what it means to people living with various types of brain diseases and functional impairments, and the factors that are most important to achieve a good life.

More white papers, strategies and action plans include measures important to good brain health, quality of life and coping from a population perspective. *The NCD strategy* (2013-2017) describes sector empowering public health work connecting lifestyle to tobacco, alcohol, physical activity and diet, and it was found that these elements also greatly impact good lifelong brain health. The presentation of a new NCD strategy is planned in 2018. *Coping with all Aspects of Life - A Governmental Strategy for Good Mental Health* (2017-2022), stresses that the most important mental health promotion arenas do not lie

within the health sector. The importance of a healthy lifestyle and healthy choices related to both physical and mental health is discussed in the strategy.

Several common and overlapping risk factors for physical and mental disorders can lead to morbidity and mortality. Multiple studies show that people with schizophrenia, bipolar disorder or severe depression live on average 15 to 20 years shorter than the general population. Although the causal factors are not fully clear, it seems that the important causes include lifestyle along with drug use.

Other strategies and plans that are important in the effort to prevent brain diseases and help improve quality of life and coping skills, include the *National Action Plan for a Healthier Diet* (2017-2021).

The plan describes ongoing and new measures for health promotion work, prevention, treatment, habilitation and rehabilitation within the services. *Many years - many possibilities. The Government's strategy for an age friendly society* also points to the importance of a healthy diet, physical activity and reduced tobacco and alcohol consumption. These factors along with age-friendly local environments and communities, volunteerism and mobilisation to combat loneliness can promote coping skills, health and the quality of life of elderly citizens. A new

action plan for outdoor activities will be presented in 2018, and the presentation of a new action plan for physical activity is planned in 2019. Both will be important in efforts to promote good brain health.

Measures that prevent violence can help prevent health outcomes caused by brain damage. This applies regardless of whether it concerns the prevention of violence against infants, for example, shaken baby syndrome, or violence that might occur in other close relationships or random violence. The prevention of violence can help reduce disorders amongst victims of violence and reduce the costs of society.

Prevention work often distinguishes between population-targeted (or universal prevention), group-centred prevention and individualised prevention. Some measures, such as a healthy lifestyle and strategies to enhance the individual's ability to cope, are important to all three forms of prevention.

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### Activity services and guide

From 2012 to 2015, the Neurology Plan 2015 had two three-year development programmes for municipalities, one programme for day and activity services and a programme for adapted exercise classes. The target population was individuals with neurological diseases or injuries. The Care Research Centre and the Norwegian Directorate of Health has developed a guide for the establishment and implementation of day and activity services, and adapted exercise classes for individuals with neurological injuries and disorders. The guide will be launched electronically early in 2018 in the Norwegian Electronic Health Library and on Nevronett.no

### Population-targeted (universal) prevention

Universal prevention targets the entire population. Lifestyle and healthy choices are central aspects in health promotion and preventive public health efforts and can contribute to good brain health throughout life. *The white paper on public health, coping and opportunities* (Meld. St. 19 (2014-2015)) outlines principles for promoting healthy choices within the population.

The most important principles for promoting good brain health and some brain disorders, such as a stroke or dementia are as follows:

- It shall be easier for people to make healthy choices.
- The coping skills of each individual shall be strengthened.
- Instruments that influence lifestyle and habits shall be used in an effective manner.

Healthy choices shall be simpler, more available and attractive. Easy access to healthy food and beverages, well-developed areas in the local community for physical activity and efforts to enhance the individual's ability to cope are the central themes. Information and campaign work are important instruments and must be designed in a way that impacts the population as a whole and the groups that need it most.

Not all brain diseases can be prevented, but the risk of brain disease and comorbidities can be reduced through a healthy lifestyle. Even when the disease has occurred, the development of the disease can be affected by lifestyle choices. Regular physical activity, healthy diet and no tobacco has a positive effect on brain health, both before and after diagnosis (Directorate of Health, 2009).

Good mental health can help patients to better cope with a brain disease once it has occurred. Good sleeping habits can help improve concentration and cognitive functioning. Sleep problems during adolescence are associated with increased mental health challenges, disturbing alcohol consumption, increased school absenteeism and lower educational performance (Norwegian Institute of Public Health, 2016).

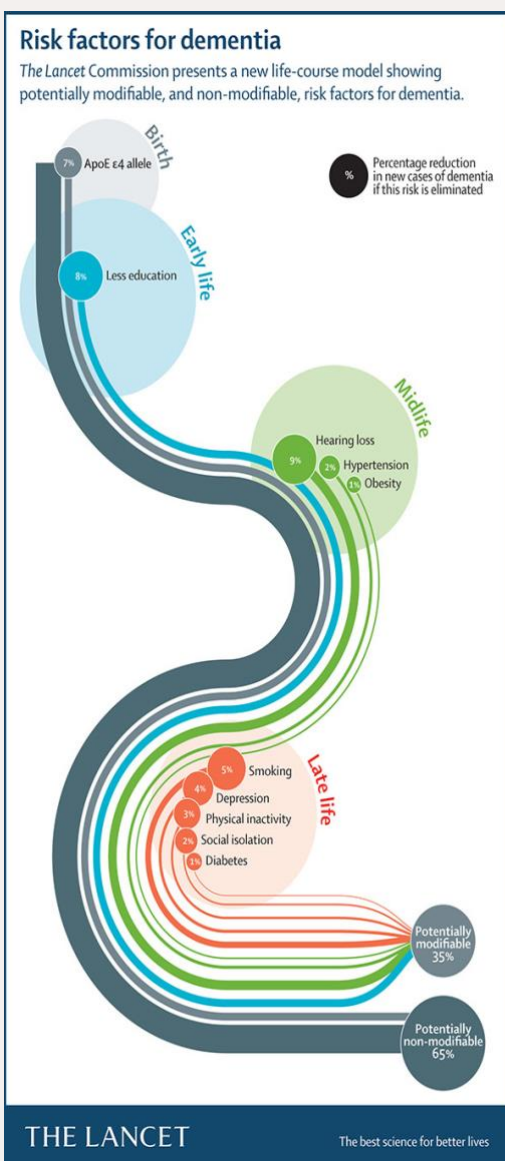
Disorders that fall within brain health vary in terms of symptoms, severity, age of onset, prognosis for the course of treatment and potential treatment.

Similarly, the potential risk factors of the conditions and the extent to which the diseases can be prevented vary. Figure 3.1 shows how the risk factors for dementia can appear throughout life and potential prevention measures. It is becoming increasingly clear that cardiovascular diseases and dementia share many similar risk factors (Aamodt and Dietrichs, 2017).

## Information and campaigns

Information and campaigns aimed at the population about the importance of making healthy choices can help reduce the risk of more brain disorders. The Norwegian Directorate of Health's campaign for more physical activity 'Your 30', and 'Small Steps - Big Difference' for a healthier diet and 'Quit' to stop smoking all constitute prevention and health promotion measures.

**Figure 3.1 Risks of dementia and potential prevention**



Information and campaigns are not limited to lifestyle. The national campaign, Talk, Smile, Lift, is aimed at the entire population, as well as those at risk of having a cerebral stroke. Information on how to prevent violence can help reduce both temporary and permanent brain damage caused by violence. Campaigns and information about psychosis and mental disorders can reduce stigmatisation and increase knowledge about mental illness, highlighting how important it is to seek help and get early treatment. The campaign, Be a Great Friend, was an anti-stigmatisation campaign. It was created by TIPS Southeast Norway, the regional competence service for early intervention with psychosis.

Campaigns often contain elements that can help to improve the individual's ability to cope.

### National Stroke Campaign

About 12,000 people undergo a cerebral stroke each year in Norway. In 2016, the Norwegian Directorate of Health carried out the first national cerebral stroke campaign amongst the population. The message was simple: Do you find it difficult to talk, smile or lift your arms? Call 113 - every second counts. The campaign has resulted in more people calling 113 with suspected cerebral stroke symptoms. The results also show an increase in the number of patients treated with blood clot dissolving medications (thrombolysis) during the campaign period compared to the same period the previous year. The campaign was repeated in autumn 2017.

### Group-centred prevention for risk groups

Group targeted measures can be useful for people who already have or at higher risk of developing a brain disease or sequelae caused by a brain disease. Many municipalities have established so-called healthy lifestyle services, as part of the municipal prevention service. These services include both group and individual-oriented prevention, and courses for living and coping with a disease. Such municipal services help people to change their lifestyle. The services

could involve guidance and adapted measures, for example, physical activity, a healthier diet and tobacco weaning. Several municipalities also have initiatives for sleep problems and coping with depression. The target group is people who already have a disease/disorder or challenges related to physical and mental health, or those at higher risk of developing such a condition. However, a patient does not need to have diagnosis or actually be ill to receive such a service. Brain diseases, such as a cerebral stroke, dementia and Parkinson's disease increase the risk of anxiety and depression, and it is an advantage if coping strategies can be offered and acquired to reduce the symptoms of anxiety and depression.

Access to the service is a so-called 'prescription for a healthy life' and gives a period of structured follow-up. GPs, health personnel or case officers at one of the Norwegian Labour and Welfare Administration's (NAV) offices can print such a prescription. People can also apply directly without a prescription and then receive information and guidance based on individual needs. A subsidy scheme has been established for the creation and development of municipal services covering healthy living, and learning and coping skills. A prerequisite for qualifying for a subsidy is user involvement when designing the service. County governors manage the subsidy. All municipalities should have services in place for patients with a brain disease; not only to help lifestyle changes, but also to cope with living with a disease. Such 'living-with' services are not an alternative to educational services for a specific diagnosis

### **Courses run by Bærum Health and Healthy Lifestyle Service**

Since 2006, the Municipality of Bærum has offered a service to people living with cognitive challenges after stroke, or other acquired head injury. The service includes learning to cope courses, courses for relatives and an activity day every week. Both the learning to cope course and activity day shall contribute to more awareness of their own injury, greater understanding and acceptance of the new situation and the courage to find solutions for everyday challenges.

## **Prevention directed at the individual for people at high risk of disease**

Prevention directed at the individual is a measure aimed at people who already have symptoms or who are at high risk of disease. It could be individuals with high blood pressure, high cholesterol or early signs of changes that might be compatible with a cerebral stroke. But it can also be people with the initial signs of a psychosis. Two-five per cent of all cerebral stroke patients experience epileptic seizures, and about half of those who have a cramp attack at the onset of stroke will experience epileptic seizures later. Anti-epileptic medication might be important in the prevention of recurring attacks (Directorate of Health, 2010).

The aim of early intervention when there is a risk of psychosis, is to prevent or delay the outbreak of psychosis in those at high risk of developing psychosis. Regular monitoring to assess symptoms and mental status, the normalisation of symptoms and psychoeducation (learning about psychotic disorders and how to cope with living with a psychotic disorder) is effective for some people. It is crucial that an untreated psychosis is not left untreated for long. Early detection and treatment of psychoses (TIPS) was developed by the psychiatric division at Stavanger University Hospital. Similar low-threshold services have now been established several places in Norway, for example, Vestre Viken Hospital, Inland Hospital and Nord-Trøndelag Health Trust.

Chronic diseases affect quality of life and can make it difficult to cope with everyday life. Learning and coping services may be useful to establish coping techniques and strategies to limit the pressure of physical and psychological symptoms and to manage any discomfort. For example, many headache patients benefit from recording factors that can trigger headaches and establish strategies to avoid them. For many, adaptation of daily life at work or school to ward off trigger factors and the opportunity to rest are essential for coping with day-to-day living.

## Prevention and treatment of headache disorders

Headache disorders are a challenge to public health, and many can obtain a better life through increased awareness and competence development, prevention and changed treatment. The European Brain Council writes the following:

*Headaches, particularly tension-type headache, migraine, and medication-overuse headache affect half of the European population. Headaches are treatable but are still significantly under-diagnosed and wrongly treated in the population. Education of primary care practitioners and pharmacists can play a key role in increasing diagnosis, proper treatment and appropriate referral to tertiary level of care for the most complex cases. Implementation of structured headache services is a good way to achieve higher population coverage. Such intervention needs support by educational initiatives aimed at both patients and healthcare providers to achieve better adherence*

[www.braincouncil.eu/wp-content/uploads/2017/06/EBC-VoT-White-Policy-Paper.pdf](http://www.braincouncil.eu/wp-content/uploads/2017/06/EBC-VoT-White-Policy-Paper.pdf)

## Sub-objectives:

- The population shall become more educated about the important aspects of good brain health and quality of life from conception to death.
- The health authorities shall highlight the importance of healthy choices for good brain health through information and campaigns.
- The local authorities, through cooperation with user organisations, the private sector and non-governmental organisations, shall develop more quality-assured services to promote a healthy life, learning and coping skills.
- Health promotion and prevention work will be increased throughout all health and care services.

## Everyday exercise with Parkinson's disease

Everyday exercise with Parkinson's disease is a three-year project organised by the Municipality of Asker in cooperation with Asker and Bærum Parkinson's Disease Association and others. The project is about educating the municipal health personnel and offering exercise classes in groups or individually. The user's own needs and goals steer the content of the services and exercise programmes. An agreement has been entered into with two physiotherapy clinicians and a speech therapist in the municipality, and all employees working within the nursing and care services have been given information, and attended training programmes and courses. The University College of Southeast Norway is heading the research part of the project. Their experiences might be of value to other people with multiple and complex needs.

*Input of the Norwegian Parkinson's Disease Association*





# 4



## Objective 2: Health and care services that are more user-centred and take better care of relatives

The Government will create a health service for the patient. This means that one must think, act and organise the health service differently. In a health service for the patient, everyone is heard and met as they are.

Security, predictability, respect and politeness are fundamental elements. The health and care services must be available to patients and users.

In a health service for the patient, the patient and health personnel are equal partners.

Patients must have access to quality-assured health

information in order to participate in decisions about their treatment, and they must have access to their own health details - "No decisions about me – without me".

The patients' needs and preferences shall be emphasised by asking, "What is important to you?" This the core question that must be asked to all patients and users. The patient's voice should also be heard in quality improvement, research and innovation. This is discussed in Chapter 6.

### Blogger Sara Riggare about the importance of coping skills

«I see my neurologist once or twice a year, about half-an-hour every time. That is one hour per year, and the rest of the year's 8765 hours, I spend in self-care. I am sure it is the same way for a lot of you out there as well. This means that I am directly in contact with healthcare's practices and clinical guidelines for my Parkinson's during no more than one hour per year. And it is only during this one hour that my neurologist can assess my symptoms, observe how my condition progresses and evaluate my status. It is also during this one hour per year

that my treatment is being prescribed, different medications and other interventions. But it is during the rest of the year's 8765 hours, that I implement the treatment. Because, let's be honest, my neurologist doesn't even know if I take the medications he prescribes. But, probably most important, it is during the 8765 hours in self-care that I can observe the effects of the treatment. And this is where self-tracking comes in."

<http://www.riggare.s>

The patients are the ones that have the power to make the changes necessary to create a health service for the patient. When the patient's knowledge and experiences are valued and used alongside professional competence to develop the service, the health and care services will be better for both the user and health service employees.

A new and improved patient and user role means that patients will be able to take more responsibility for their own health, treatment and care. User-centred healthcare will make it easier for the patient to cope with living with a disease. People with neurodegenerative disorders tend to find it most difficult to cope with the unpredictability of the disease cycle.

### Helsenorge.no - your online health

Health authorities have a responsibility to give the public access to quality-assured health information.

*Helsenorge.no* has its own theme pages, for example, cerebral strokes and mental health. *Helsenorge.no* also publishes user-friendly information about the quality of the healthcare services. The national quality indicator system contains several indicators for cerebral strokes, mental health and day activity services, etc.

Access to your own health details is available through the 'My health' service where patients can access their medical records at the hospital via a secure login system. Currently, only patients of the Western and Northern Norway Regional Health Authorities have access to this digital service. All Norwegian citizens have access to their main medical records with important health information and to 'My prescriptions'. More digital citizen services are under development.

Patient organisations play an important role in the development of quality-assured information about diseases and coping strategies. Subsidies are given to user organisations to give people with neurological injuries and disorders guidance and information.

### Short film about epilepsy

The Norwegian Epilepsy Association has made a series of 16 short films to answer the most frequently asked questions about epilepsy. The films have been published online and on social media platforms. The Norwegian Epilepsy Association and users were involved in the work. A total of 16 questions are answered in the series of films, and the episodes were made in both Norwegian and English to reach the widest possible audience. The objective is to make information about epilepsy more accessible.

[www.epilepsi.no/aktuelt/hva-er-epilepsi](http://www.epilepsi.no/aktuelt/hva-er-epilepsi)

### Patient engagement

Patient engagement means that patients and health professionals work together to make decisions about diagnosis, treatment and monitoring to the extent and in the ways that the patient wants. Patient engagement will be relevant when there are several options available with differing advantages and disadvantages. The patient is given support to assess the options based on the best available information about efficacy, the advantages and disadvantages, and to discover their own values and preferences. The objective is to agree about the option that best suits the patient's own wants and needs.

Patient engagement tools have been developed to aid the patient engagement process. Patient engagement tools help patients to obtain relevant and reliable information about his/her health problems and subsequent options available. The Southeastern Norway Regional Health Authority is currently developing a patient engagement tool for patients with bipolar disorder. Patient engagement tools can also be useful for other patients with a brain disease, but they must be adapted for patients with cognitive failure.

### ParkinsonNet - networking between patients and professionals

ParkinsonNet was developed in the Netherlands, as a nationwide service for patients with Parkinson's disease. The objective of ParkinsonNet is to give people with Parkinson's disease optimal treatment and the best possible support from professional and competent

professionals, who consider the patient a partner. The model enables patients to come into contact with networks with multidisciplinary competence in close proximity to their own home. ParkinsonNet is built on the foundation that professionals shall receive systematic training within the network, and that patients shall obtain information about their disease, adapted self-care and treatment in order to cope with living with a disease.

In the Netherlands, each professional is linked to a network according to their profession comprising of other people connected to ParkinsonNet with the same professional background, for example, physiotherapists. The number of interconnected professionals in a monitoring team will vary from patient to patient. Multidisciplinary cooperation and the patient's needs are central to this type of monitoring. A future Norwegian model might involve a team of professionals that the patient is already in contact with, for example, a neurologist, physiotherapist, ergotherapist, a nurse specialising in Parkinson's disease and a speech therapist. For someone else, it might be more appropriate to have a team of neurologists, physiotherapists and psychologists.

A two-year pilot project was started in 2017 to develop a Norwegian version of ParkinsonNet in Stavanger. A similar project will be started in Oslo in 2018.

The pilot project will involve the establishment of a professional network for physiotherapists, ergotherapists and speech therapists, all of whom will receive systematic training. The networks will interact with each other and other professionals in the specialist health service and municipal health and care services. The pilot project will evaluate how this method of working functions in a Norwegian context, and which tools and structures are necessary to enable the networks to best serve the patient.

### **Personalised services, activities and respite care**

Some brain diseases lead to cognitive changes making it potentially difficult for a patient to function socially and in his/her daily life. Activities are important to maintain functioning and to slow the progression of many brain diseases.

From 2020 it will be mandatory for the municipalities to have offer day activities to people living at home with dementia. Many municipalities have already established such a service. Day activities relieve relatives, whilst the patient participates in adapted activities. Some patients have refused to have the service, as some of them associate it with shame and taboos. The service must be further developed so that users will want to accept such a service, and more openness about progressive brain diseases is essential.

### **User-controlled personal assistance**

Municipalities shall offer practical assistance and training organised as user-controlled personal assistance (BPA). BPA is a way of organising services in a way that allows everyone with a functional impairment to live as actively and independently as possible. BPA contributes to equal worth, equality and social participation for people with a brain disease and reduced functional ability, who require a lot of assistance.

In 2015, BPA was incorporated into the Norwegian Patients' Rights Act, as a legal right. The amendment gives people under the age of 67 with a long-term and great need for personal assistance, the right to BPA. The right also includes respite care initiatives in accordance with the Norwegian Health and Care Services Act for people with parental responsibility for children under the age 18 with reduced functional ability living in the family home. Municipalities are also obliged to consider whether it is appropriate to offer BPA to users who do not meet the requirements of the provision governing this right.

### **Support and guidance for relatives**

Relatives are an invaluable support and resource to their loved ones, as well as to society. Relatives who take care of their loved ones shall be welcomed by the public services, who shall work with them, coach and support them, and provide respite care when needed. Many children take on the role of a grieving relative during adolescence. Children in this situation must be taken care of; they must not take on the role of a carer.

When children become the grieving relative with a brain disease, they are exposed to special challenges. The disease cycle is characterised by sudden

## Ottestad model - a spokesman for relatives of people with dementia

The University College of Hedmark has cooperated with Ottestad Nursing Home in the Municipality of Stange to develop a model to strengthen user participation when caring for people with dementia. Since more of the users are unable to safeguard their own interests, relatives are considered their spokespersons and representatives. Objectives of the Ottestad model:

- To safeguard fulfilment of the needs of relatives with regard to information, cooperation and follow-up.

- To increase the user participation of patients and relatives.

The evaluation of the model shows, for example, that the patient and relatives are better cared for, and they receive better information through systematic verbal communication.

<http://www.utviklingssenter.no/ottestadmodel-len-en-%C2%ADmodell-for-samarbeid-med-pasient-og-paaroerende.5795592-185702.html>

loss of bodily functions or deterioration, which could contribute to uncertainty and unpredictability. Information services and materials that are adapted to children and young people are important to help ensure that children can cope with their daily lives, as a grieving relative. In the event of a severely progressive neurological disease, it is particularly important to ensure that the needs of children to receive information, security and support are secured. The Norwegian ALS support group has created a peer group for children and young people up to the age of 25. The group is on Facebook.

One of the objectives is that the efforts of relatives shall be highlighted and valued. Relatives shall also be offered the necessary support and respite care. The Next of Kin/Relative Programme 2014-2020 aims to improve the conditions of informal care and interaction with the public authorities. Proposition 1 S (2017-2018), proposes to include children in the programme. It has been proposed to allocate an additional NOK 5 million to the Pårørendesenteret (centre for relatives) in Stavanger. More information about the centre is available on their web site [www.paarørendestavanger.no](http://www.paarørendestavanger.no). The Norwegian Directorate of Health has published a guide on relatives' rights and the

obligations of the health and care services, and children, as grieving relatives, are also discussed. The Norwegian Directorate of Health's circular, *When Children become the Grieving Relative*, is a guide for health personnel, who are duty-bound to take care of minors when they are the grieving relative.

A new provision in the Norwegian Health and Care Services Act obligates municipalities to offer the necessary support to grieving relatives in the form of respite care, training and guidance, in addition to dependent care benefits. The duty of municipalities to assess the needs of relatives and pass administrative decisions on which action to take, is more transparent. No changes have been made in the provision regarding the duty to give general information

and guidance pursuant to other provisions of law regarding next of kin/relatives.

In 2017, a NOK 7.5 million subsidy from the Dementia Plan 2020 was given to municipalities that arrange schools for next of kin/relatives and support groups - and as a subsidy to people who participate in national courses for relatives of younger people with dementia.

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## **BarnsBeste – competence network for children as the grieving relative**

BarnsBeste was created in 2007 by the Norwegian Ministry of Health and Care Services to develop measures for children, who become the grieving relative. It is a nationwide network responsible for:

- gathering, systematising and conveying information and their experiences of children as the grieving relative;
- ensuring that the services comply with applicable legal requirements;
- facilitating competence enhancement through research and professional development;
- helping to advise the authorities, services and partners;
- helping to increase knowledge about what it is like to live with a parent's disease or injury and how to best care for children.

BarnsBeste is organised by the Southeastern Norway Regional Health Trust and is located at Sørlandet Hospital.

[www.barnsbeste.no](http://www.barnsbeste.no)

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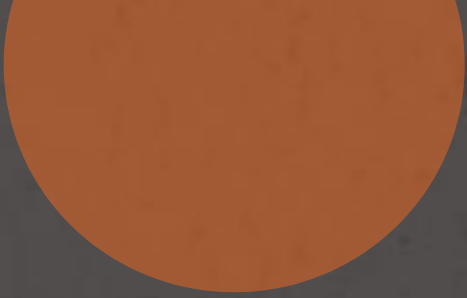
### When a mother or father has MS

About 11,000 people have MS in Norway with the onset of symptoms usually appearing between the age of 20 and 40 years. Many children and young people are therefore the grieving relative of a parent with the diagnosis. A web site, *MSpårørende.no* and online self-help programmes have been created for children and young people with a parent with MS. The programmes aim to get children and young people to verbalise their thoughts and feelings to their parents about living with a disease in the family.

<http://www.ms.no/nyheter/barn-og-unge-som-paaroerende-ny-nettside-gir-hjelp>

### Sub-objectives:

- Patient engagement tools should be created for patients with a brain disease to enable patients to actively participate in decisions regarding diagnosis, treatment and monitoring.
- Patients are actively involved in the preparation of quality-assured health information regarding diseases and coping strategies.
- A broad professional network should be established, which, unlike the model on ParkinsonNet, should not be limited to diagnoses.
- Services, activities and respite care is adapted to each patient/user
- Relatives and children as the grieving relative receive proper follow-up and guidance.



# 5



## Objective 3: Good care from the onset of symptoms to diagnosis, habilitation and rehabilitation

Most patients with a brain disease require repeated contact with hospitals, other specialist health services, their GP and other municipal health and care services. Several have complex needs and live with one or more chronic diseases. These patients need subsidiary services to work well together, so that patients and families receive a uniform and coordinated service.

The objective is a uniform chain of patient care, regardless of who is responsible for each subsidiary service. *The white paper on primary healthcare* (Meld. St. 26 (2014–2015)) and *the National Health and Hospital Plan* (Meld. St. 11 (2014-2015)) describe the simultaneous challenges of fragmented services. Patients and relatives are finding that they need to coordinate various services themselves.

Changes in disease patterns requires changes in the way the health and care services interact and work. The white paper on primary healthcare points out the need for restructuring of the health and care services to make them more team-based. The National Health and Hospital Plan makes demands in terms of the distribution of tasks and uniform patient care through cooperation in networks.

The transition from childhood to adulthood is especially challenging. Patients, who have been followed up by paediatric departments and the habilitation service for children and young people, are offered a more fragmented service from the specialist health service as adults. Life cycle transitions must be planned well in advance and professional departments in the specialist health service and municipalities must be involved before the child turns 18.

The Government has presented several strategies, guides, guidelines and action plans, which combined shall contribute to better patient care.

### **How the department of neurology in Molde distributes tasks**

The Department of Neurology's outpatient clinic at Molde Hospital had long waiting lists, but when nurses specialising in epilepsy took over the monitoring of patients, the waiting lists were greatly reduced. Such initiatives benefit the patients, encourage more interdisciplinary cooperation and spread know-how around the department.

*Input of the Norwegian Brain Council*



## Sub-objectives:

- Leaders of the municipal health and care services and specialist health service must follow-up routines for the coordination of services for users with complex needs.
- Municipal health and care services and the specialist health service must have good routines for the life cycle transition from adolescence to adulthood.

## Primary healthcare shall be more team-based

Municipalities shall ensure that all citizens are offered the necessary health and care services. To fulfill their responsibilities, municipalities shall provide services to enhance their preventive healthcare, diagnostics and treatment, rehabilitation, nursing and care, as well as assistance in the event of accidents and emergencies.

Many users need a broader professional service and better coordinated services. Poor cooperation could lead to unnecessary waiting times, interrupted care and less ability to cope with a disease. To ensure that the municipalities have the necessary key competencies, they must from 2018 have partnered up with doctors, nurse, physiotherapists, midwives and health nurses. From 2020, they must also have an ergotherapist and a psychologist. A clinical nutritionist could also be an important resource.

The Government has also introduced a requirement for specialisation in general medicine for doctors working in the municipal health and care services.

GPs play a central role in the monitoring of people with brain disease. GPs are responsible for coordinating professional medical services to citizens on their list, and they shall cooperate with other relevant service providers. Municipalities shall facilitate cooperation between GPs and the specialist health service. GPs have a duty to inform patients who need long-term, coordinated services of their right to receive an individual plan and coordinator from the municipality. GPs shall help prepare and assist with other follow-up related to the individual plans of their patients. Municipalities are responsible for appointing a coordinator for the individual patient/user. In most cases it will be necessary

for GPs to talk to and cooperate with the coordinator and vice versa. If necessary, GPs shall refer their patients to the specialist health service and other municipal health and care services.

Municipalities will be able to try new working methods, for example, in the form of a primary healthcare team or monitoring team. A more team-based primary healthcare service can give a broader and more coordinated service, better availability and better utilisation of personnel resources. Many municipalities already offer team-based monitoring, but it is often linked to the diagnosis.

People with a rare diagnosis, such as ALS, will therefore not always receive the monitoring they require and are entitled to. In a primary healthcare context, diagnosis affiliation is neither scientifically correct or sustainable, thus team-based monitoring must be facilitated based on needs and functional ability.

Primary healthcare is an extended general practice where multiple professions work together to provide basic healthcare to the patients on the GP's list. Primary healthcare consists of a doctor, nurse and medical secretary. The organisation of teams will lead to better services to, for example, people with a brain disease and others who need closer monitoring, education and coping skills. The testing of primary healthcare teams will, as planned, start in spring 2018 for a duration of three years. The following municipalities will test primary healthcare teams: Seljord, Ørskog, Flora, Malvik, Kristiansand, Ringsaker, Eid, Rana and Oslo with the boroughs of Alna, Nordstrand and Sagene.

Monitoring teams provide a more systematic way of working interdisciplinarily. A monitoring team will consist of various professionals, depending on what services the individual needs. Pilot monitoring teams are currently being planned with the intended start-up in 2018. During testing, tools that can identify people who might need comprehensive assistance from the health and care services, shall be used. The Norwegian Directorate of Health has prepared a guide on how the municipalities should organise services for users with extensive and complex needs.

The transfer of tasks from the specialist health service to the municipal health service allows more people with brain

disease or neurological injury/disorder to be treated by municipal services. This elevates municipal competencies. The Government's plan *Competence Elevation 2020* includes several measures to assist with this, for example, subsidy schemes to strengthen the sharing of information and competence on neurological diseases, and subsidies for general and continuing education for employees of municipal health and care services.

### **The Municipality of Bergen's primary healthcare team**

The primary healthcare team in the Municipality of Bergen consists of a nurse, an ergotherapist and physiotherapist. The team was initially established in connection with a research project linked to the rehabilitation of stroke patients. When the project was over, it was established as a permanent rehabilitation service, and there are now four primary healthcare teams in the municipality. The service of primary healthcare teams was extended to include MS patients a few years ago. The service is personalised and might include mapping of a patient's ability to function, targeted exercise, self-exercise and motivational guidance, psychosocial support, health promotion measures and assessment of the need for an adapted dwelling.

[www.bergen.kommune.no/omkommunen/avdelinger/innsatsteam-rehab](http://www.bergen.kommune.no/omkommunen/avdelinger/innsatsteam-rehab)

patient's home.

The service should be given as an integral part of the user's life at home, school, nursery school, day care, in the workplace or recreational venues in residential and local areas. For many people with a brain disease, rehabilitation is a lifelong process. They will experience functional improvement and functional deterioration that necessitate lifelong training and rehabilitation. Therefore, the Government will change the definitions of habilitation, rehabilitation, individual plans and coordinator to clearly indicate that the user may need such treatment throughout his/her life

### **Sub-objectives:**

- Create interdisciplinary and coordinated services based on the patient's wants and needs.
- Team-based services within the municipality shall be developed based on the user's needs and functional ability.

### **Habilitation and rehabilitation**

People with brain disease or brain damage often require habilitation and/or rehabilitation. Good rehabilitation is also about the feeling of being able to cope.

The Government's *National Habilitation and Rehabilitation Programme (2017-2019)*, intends for most habilitation and rehabilitation to be given locally in the part of the municipality where the patient lives. Children shall be given the opportunity to attend school and recreational activities even during the rehabilitation process, thus it must be arranged in the vicinity of the

*The Habilitation and Rehabilitation Plan (2017-2019)* includes a number of measures, which in the longer term will enable municipalities to offer good habilitation and rehabilitation services to patients.

The plan also includes measures for the specialist health service and better patient care when interchanging between the specialist health service and the municipalities, for example ParkinsonNet (discussed in Chapter 4).

The escalation plan's focus on children with brain damage caused by accident or illness, is followed up by a project that aims to prevent unwanted variations to ensure that the children receive good quality care throughout the course of treatment. The regional health authorities have been earmarked funds to improve the treatment for children with acquired brain injuries.

The regional health authorities have also been commissioned to strengthen hospital outpatient services to meet the competence requirements of users and the municipalities.

### **Multidisciplinary outpatient habilitation teams for adults**

People with mental retardation and autism may have challenging behaviours, for example, self-harm. Relatives and personnel in dwellings might have little experience with such problems. The University of Oslo has a multidisciplinary outpatient team that can be in placed for a prolonged period of time to observe behaviour and functioning. The team assesses the need for assistance and measures, and gives guidance to relatives and personnel in dwellings and at the workplace. The team provides important support in situations where an alternative to the use of force and coercion is paramount.

*Input of the Norwegian Brain Council*

### **Sub-objectives:**

- Patients in need of habilitation and rehabilitation will be offered such services in their own municipality.
- Hospital outpatient services shall support municipal services to care for users who live in their own home.
- Implement national treatment programmes for children who have acquired a brain injury.

### **Use of individual plans and coordinators**

Patients and users who need long-term, coordinated health and care services have the right to receive an individual plan. Many users with a brain disease will require long-term health and care services. As such, coordinating the services with the actors whilst taking care of the family can be demanding. The coordination of patient care is essential for good transitions.

Individual plans are not used enough in the health and care services and are poorly followed up by the municipalities and specialist health service. Users and their relatives are finding that they must coordinate the services themselves. More people could have had a better life and there would be fewer admissions to hospital if the content and organisation of the municipal health and care services, and the interaction between the various tiers, were better adapted to patients' needs. One of the problems is that electronic individual plans cannot be transferred between the different tiers of services and across sectors. This prevents users from receiving the broad scope of the service in the plan. In the Government's strategy for good mental health, *Coping with all Aspects of Life*, measures have been proposed to improve the coordination of services.

The Norwegian Directorate of Health's guidelines on rehabilitation, habilitation, individual plans and coordinators is aimed at health personnel, who will be offering habilitation and rehabilitation in both the municipal and specialist health services. It is also aimed at other sectors. The Director of Health's guide on how the municipalities shall follow-up patients and users with significantly complex needs, points out the need for clear managerial support in its efforts to secure good coordination, which includes an individual plan and coordinator for patients and users in accordance with legislation.

Coordinating units in charge of habilitation and rehabilitation are responsible for the individual plan and coordinator scheme, in addition to appointing and giving advice to coordinators. Several coordinating units have developed a good system for training and guiding coordinators, however, this needs to be reinforced, for example, with e-learning programmes. In cooperation with the services and users, the Norwegian Directorate of Health has initiated efforts to develop a national e-learning programme for coordinators.

### **Sub-objectives:**

- Ensure that patients and users with a long-term need for coordinated services exercise their entitlement to an individual plan and coordinator.

### **The Dementia Plan 2020 – systematic monitoring after diagnosis**

The Dementia Plan 2020 follows up Dementia Plan 2015. Many of the measures in the plan have been implemented in most municipalities. The majority of the national professional guidelines on dementia have been completed with the following topics: general diagnosis, medical treatment and close systematic monitoring after diagnosis.

The second part will be completed in 2018. It is important that policies are implemented and regularly updated. Many symptoms and loss of functional ability with dementia will also occur with other brain diseases. The guidelines can therefore be used for other brain diseases that lead to cognitive impairment. The right to an individual plan and coordinator is emphasised, at the same time as a model programme for systematic monitoring after diagnosis is being tested. Fifteen projects have been subsidised and the participating municipalities receive follow-up along the way. The project groups consist of the Norwegian Directorate of Health, the National Association for Public Health and the Norwegian National Advisory Unit on Aging and Health.

The development project, *New home care models for people living at home with dementia*, started in spring 2017. The project shall further develop home care, so that the general instruments used by the municipal health and care services take into account the need for special adaptation for people with dementia and their relatives.



'Demensomsorgens ABC' (the ABC of caring for patients with dementia) is a training package for municipal employees who work with patients with dementia. Another measure in the Dementia Plan 2020 is user and next of kin schools to help them come to terms with a dementia diagnosis in their daily lives. Such courses are also available to spouses and children of younger individuals with dementia.

### Sub-objectives:

- The Norwegian Directorate of Health follows up and evaluates the measures of the Dementia Plan 2020, the use of adapted home care, systematic monitoring after diagnosis and day activities.
- Increase the utilisation of the measures in the Dementia Plan 2020 to cover more target groups.

### Treatment packages for cerebral strokes, mental health disorders and substance abuse

A package treatment is a standardised course of treatment that describes the organisation of the diagnosis procedure and treatment, communication with the patient and relatives, as well as the assignment of responsibility and specific treatment periods. Objectives of treatment packages:

- The prevention of unnecessary non-medical delays in connection with diagnosis, diagnostics, treatment and rehabilitation.
- Equal services to patients and relatives, regardless of where they live in Norway.
- Good information and increased user participation and satisfaction.

In 2015, the Norwegian Directorate of Health was commissioned to create a package treatment for cerebral stroke patients. The package treatment is based on the revised guidelines for the treatment and rehabilitation of cerebral stroke patients to ensure that they comply with the latest knowledge and research. The package treatment from emergency treatment to the time of admission to a stroke unit will be presented at the end of 2017. The Norwegian Directorate of Health will also develop treatment packages for specialist and municipal rehabilitation. Both the specialist health service and municipal health and care services are key actors in the securement of good patient care. Good services after discharge from hospital are important to a patient's quality of life and ability to cope.

In 2016, the Norwegian Directorate of Health was commissioned to prepare treatment packages for mental health disorders and substance abuse. The treatment packages shall help secure equal treatment, awareness of the patient's resources and better coordination at all levels. The treatment packages shall also secure better care of somatic health and healthy lifestyles. Furthermore, the treatment packages will also be useful to the referring party, as they will give him/her predictability. User organisations and professional environments in all parts of the health service shall participate in designing treatment packages. The treatments are built on national and international professional guidelines and guides; the best available information and professional consensus. The first package treatment will be ready for implementation in the specialist health service and municipalities in 2018. Children, as the next of kin, are mapped during course of treatment.

### Professional network for Huntington's disease

Huntington's disease is a rare and slowly progressive disease. The need for services constantly changes and it often extends over many years. The disease causes major challenges for the affected families and the municipal health and care services. Many of those affected by the disease have children at home, who need the care and attention of their parents. The disease can cause impaired ability to care for their own children. The Norwegian Ministry of Health and Care Services finances a professional network to increase expertise within the nursing and care services for patients with the disease. Five resource centers

are members of the nationwide network. The National Association for Huntington's Disease and the Centre for Rare Disorders are members, and NKS Kløverinstitusjoner AS coordinates the technical network. The network brings together users, municipalities, national competence services and a voluntary non-profit organisation. The cooperation secures the competence of patients and relatives, and contributes towards the competence enhancement of municipal personnel.

<http://fagnettverkhuntington.no>



The model with treatment packages for cerebral stroke patients, mental health disorders and substance abuse has a number of elements that can be developed for treatment packages to better improve the investigation procedure and treatment of other brain diseases (Directorate of Health, 2017).

optional treatment. The scheme further expands the treatment options of children with cerebral palsy and other brain damage.

### **Sub-objectives:**

- Consider developing a common course of treatment for groups of brain disease patients with similar functional impairments and monitoring requirements.

### **Brain damaged children and youths**

Cerebral palsy (CP) affects about 150 children each year. A monitoring programme provides an overview of treatment. Intensive training is important for many children with CP. The provision of intensive training varies and many want to be closely monitored. About 75 children and young people with brain injury participated in treatment overseas in 2016. Many of whom have cerebral palsy. The regional health authorities shall start work on an initiative to develop new treatment in Norway. The new services will be designed in cooperation with users. Treatment programmes for children with brain damage have in recent years been established by the University Hospital of North Norway, Oslo University Hospital and Sørlandet Hospital. The monitoring of CP in Norway is an example of good quality and systematic work. Such programmes produce results, and the aim is to ensure that all children with CP in Norway receive equal monitoring from the health service.

In 2017, the Government allocated funds for continuity in patient care for the treatment and rehabilitation of children and young people who sustain brain damage early in life (acquired brain injury) due to a disease or accident. The specialist health service, the municipal health and care services, schools, kindergartens and several other actors must participate in this rehabilitation.

In 2017, intensive rehabilitation of children up to the age of 16 with significantly reduced functional ability caused by congenital or early acquired brain damage, was included in the scheme's



## Sub-objectives:

- Develop the offer of treatment for children with brain damage through regional health authority initiatives and optional treatment.
- Maintain treatment programmes overseas for children and young people with brain damage until the regional health authorities can offer different healthcare in Norway.

## Good patient care through learning networks

The development of learning networks is an ongoing project of the Norwegian Association of Local and Regional Authorities (KS), the Norwegian Institute of Public Health and the Norwegian Ministry of Health and Care Services. When working with learning networks, it has been possible to systematise the services to provide good patient care and to document the quality of services. The learning networks facilitate professional enhancement and tools for improvements. They can also stimulate the sharing of

research, development of knowledge, competence enhancement and improve quality across all disciplines and professions. Moreover, they have also contributed to better interaction and employment of new information and methods. The networks are particularly useful for small municipalities, as they can they get access the information and expertise that they do not always possess themselves. There are many kinds of learning networks, and KS has established three that are especially important for users of the municipal health and care services.

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### Turbo in Bergen

In 2017, the physiotherapy centre for children/Turbo in Bergen, was approved for intensive rehabilitation of children up to the age of 16. The physiotherapy centre for children is pioneering in that it has made it possible for children with cerebral palsy and other brain damage to choose a treatment that is more complex and specialised than the physiotherapy treatment offered in their home municipality. For some families, the treatment offered by Turbo could be an alternative to treatment programmes overseas.

<http://turbo.bfsnett.no/site.php?q=168&tclD=168>

- National learning networks for good patient care for the elderly and chronically ill.
- National learning networks for good patient care for mental health disorders and substance abuse.
- National learning networks for good interaction for children and young people

The individual's problems do not become visible through simply giving a diagnosis. The learning networks are based on a health promotion approach, an enhanced user role and *"What is important to you?"* Learning networks and adaptation teams have proven to be effective and should be used more widely in the future.

### **Sub-objectives:**

- More health personnel within the municipal health and care services shall use learning networks.

### **Palliative care - end of life care**

Brain diseases have different prognoses and will to a varying degree shorten a person's life. Certain disease cycles, for example, ALS and Huntington's disease, severely shorten the patient's life.

Patients with brain diseases will therefore need palliative care, adaptation and pain relief.

Specialist palliative care services have primarily been offered to people with cancer. The inclusion of patients groups is also necessary. A public committee shall submit a report on palliative care in December 2017.



# 6



## Objective 4: Adequate knowledge and quality through research and innovation

The health and care services should be characterised as having adequate knowledge and quality built on research and innovation. We need more information about the frequency of brain disease within the population, diagnostics, effective treatment, rehabilitation, and how best to live with a disease or loss of function due to disease or injury. For diseases such as ALS, dementia and Parkinson's disease, we do not have enough information about the causes of the disease or effective treatment. Nor do we have adequate mechanisms for sharing the results and innovations of professionals within the health and care services.

Health and care services are constantly developing and expectations in terms of the competence of health personnel change accordingly. Research helps improve skills of health professionals. Information obtained from research needs to be reflected in education programmes and in the professional practice of health personnel.

### Relevant research Norway

Norway has a long and strong tradition in research on the brain, and the brain and nervous system's structure (basic neurological research) and

diseases affecting the brain. Research in Norway has contributed to new information within several clinical research areas such as cerebral strokes, MS, Parkinson's disease, epilepsy, dementia and mental disorders. We also have high expertise within genetic research and research on brain biomarkers.

The universities mainly carry out such research, in addition to the Norwegian Institute of Public Health and hospitals. Two centres of excellence have been established within the field, i.e. the Norwegian Center for Mental Disorders Research (NORMENT) and the Centre for Neural Computation (CNC), both of which are funded by the Norwegian Research Council. In addition, the K. G. Jebsen Foundation has funded several relevant health research centres at faculties of medicine and university hospitals.

### Need for translational research

The strong basic research environments provide a good basis for the transfer of basic research results to new diagnostic methods and treatment, so-called translational research. Cooperation between universities, university colleges and the specialist health service is necessary to enable translational research



to develop better diagnostic methods and treatment. This is partly done through a Norwegian Research Council programme titled, *Good and Accurate Diagnostics, Treatment and Rehabilitation*. The programme targets areas with a high disease burden, for example, mental health disorders, substance dependence, and diseases affecting the brain and nervous system.

### Need for clinical research

The testing of new treatments for brain disease should be better facilitated through clinical trials to help improve patient care for the included patients. These trials shall improve existing treatment and/or develop and evaluate new treatments. The Government wants to increase the scope and number of clinical trials in all disciplines. A key measure is the creation of software for clinical research within the specialist health service in 2016 - a measure that covers all the regional health authorities. The programme will give more patients the opportunity to participate in clinical trials, and improve the coordination of competence, resources and infrastructure, as well as strengthen the basis for high quality, effective and safe health services. The regional health authorities shall give patients throughout the country equal and additional opportunities to participate in clinical trials in Norway and overseas. Information about all current and planned clinical trials should be available on *helsenorge.no*. The web site also gives information on how to proceed if a patient wants to participate in a trial.

Clinical trials and rehabilitation studies should also facilitate stem cell treatment for MS, and diet and exercise interventions for dementia.

### Need for research on the services

Information about brain health in the health and care services varies greatly. This applies to both information about the efficacy of a specific treatment and the effect of the services in terms of organisation. The services research is needed to show how the services are offered to patients and how the different sections of the service interact.

### Research on neurohabilitation

Some disciplines have been poorly researched, for example, paediatric habilitation. Paediatric habilitation mainly concerns the treatment of congenital or early acquired diseases of the brain and spinal cord. The *action plan for the habilitation of children and young people*, points out that research on habilitation has been fragmented and that treatment has been poorly documented (Directorate of Health, 2009). Therefore, a national network for research on habilitation was created in 2010. The network has helped to boost research in Norway, but at the same time it is expressed that more research, research cooperation and networks are needed. The network is an affiliate of the European Academy of Childhood Disability (EACD).

### Using registry data

Excellent health and quality registries are available for use in research when looking at the effect of measures or changes in population over time. The central health registries, clinical quality improvement registries and national quality indicators are discussed later in this chapter.

### International research cooperation projects

Norway will participate in more Nordic and international research cooperation projects, for example through the EU research and innovation programme. A separate European joint programme has been established, i.e. the *Joint Programme Initiative – Neurodegenerative Disease Research*.

This is the largest global research initiative that has ever been created to meet the challenges of neurodegenerative diseases. The programme was established, because the evidence to support existing knowledge is poor and we face substantial health challenges. It is also necessary to coordinate research efforts and resources to obtain new information as quickly as possible. The objective is to find the causes, develop treatment and identify good treatments for patients with neurological degenerative diseases.

Norwegian patients will be able to participate in international trials through the EU and at the National Institute



of Health in the United States. Therefore, it is essential to continue the commitment towards competence enhancement and strengthening of the infrastructure of Norwegian research environments to facilitate the execution of clinical trials in hospitals.

## Research and innovative brain health

The Norwegian Ministry of Health and Care Services is funding three research and innovation programmes through the Norwegian Research Council. All of them are relevant funding sources for research on brain health. This also applies to several of the sector-neutral programmes, such as the *Free Project Support Programme* and the *National Commitment to Research Infrastructure Programme*, which are funded by the Norwegian Ministry of Education and Research.

Figure 6.1 shows the distribution of research funds for research on the brain and central nervous system from the Norwegian Research Council from 2011 to 2016. The funding amounts to NOK 584 million. Much of the research is aimed at causes, disease mechanisms and diagnostics, whilst significantly less is aimed at treatment and monitoring of the diseases. In addition, the regional

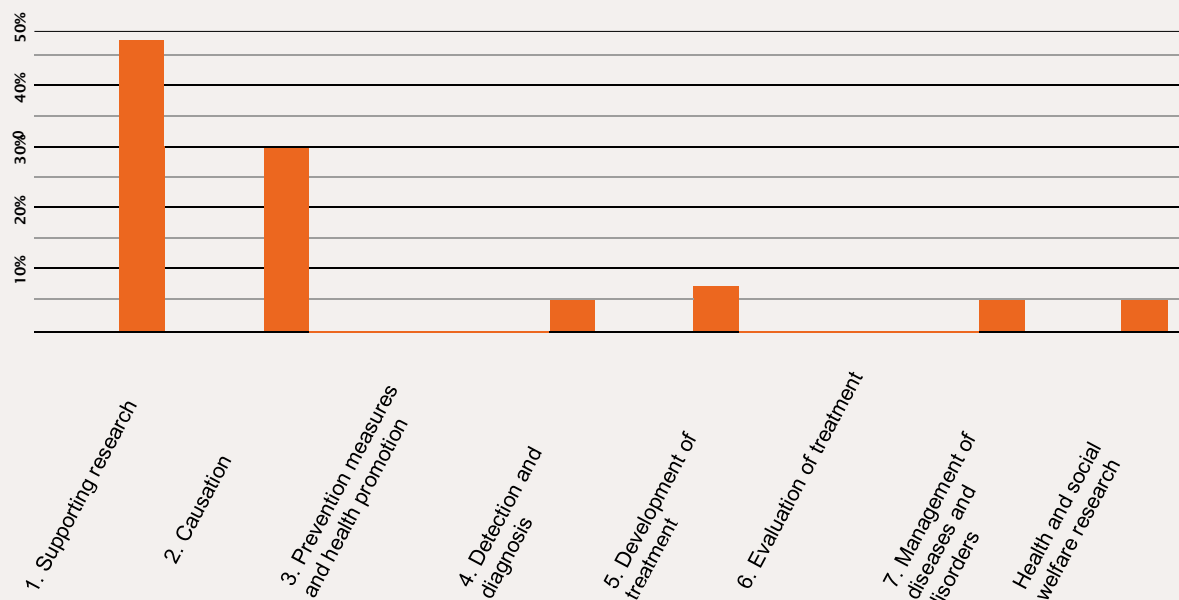
health authorities also fund research on brain health. Research on disciplines within the primary healthcare is also funded, for example, by FYSIOPRIM at the University of Oslo, which receives funds from the continuing and further education fund for physiotherapists.

*The research programme for better health and quality of life (BedreHelse) shall help to improve health, enhance the quality of life and reduce social inequalities within healthcare. The development and strengthening of initiative research is high priority. Special attention is paid to mental health disorders, neurodegenerative diseases, substance abuse and dependency, as well as life cycle transitions, periods of vulnerability and life events.*

The programme for *good and accurate diagnostics, treatment and rehabilitation* (treatment) shall particularly highlight diseases that are especially challenging to society, for example, dementia. It shall contribute to increased use of health and quality registries, health surveys, biobanks and sharing of data in clinical trials. It shall also promote translational research when knowledge-based treatment is inadequate. The programme shall also promote personalised medicine, including stem cell treatment. The Government will strengthen the pro

**Figure 6.1 Distribution of funding for research on the brain and central nervous system**

HelseOmsorg21-monitor [www.helseomsorg21monitor.no](http://www.helseomsorg21monitor.no)







programme with the allocation of NOK 5 million. Reservations are made against the handling of the national budget by the Norwegian Parliament.

The *Health, Care and Welfare Services Research Programme* (HelseVel) shall contribute to research and innovation of quality, competence and efficacy of the services. The programme highlights several problems that can be linked to brain health, for example, patient care, care research and innovations through welfare technology, etc. Other projects could be aimed at the interaction between the health and care services, and the labour and welfare services.

### Joint program for research on neurodegenerative diseases

The joint programme, Neurodegenerative Disease Research, is an ambitious global research initiative to obtain more information about neurodegenerative diseases. Norwegian researchers are participating in the programme. The professional research priorities include:

- the cause of neurodegenerative diseases;
- disease mechanisms and disease models;
- disease definitions and diagnoses;
- treatment and prevention;
- health, care and welfare services.

Norway earmarks funds for the programme and is participating along with 27 EU and EEA countries, as well as Canada, Australia and Switzerland. Research networks and databases have been established, in addition to an overview of the research activities of all the countries within this field. The overview shows that better coordination of research efforts and the identification of research gaps is required. User participation is emphasised in the programme. Program priorities include Alzheimer's disease and other dementia disorders, Parkinson's disease, prion diseases, motor neurone diseases (including ALS) and Huntington's disease.

In 2017, the Norwegian Research Council prepared a strategy to secure good coordination between national research on neurodegenerative diseases and research funded through the European joint programme. The strategy proposes to establish a national network that secures better coordination and exploitation of resources.

### New scheme for clinical research centres

The Government will commit to outstanding brain research connected to national and international networks. A proposal has been made to allocate NOK 20 million in 2018 to a scheme for clinical research centres. This is a multiyear commitment. Reservations are made against the handling of the national budget by the Norwegian Parliament. The first announcement from the Norwegian

Research Council will prioritise the establishment of a clinical research centre for serious diseases of the central nervous system, such as ALS, MS and dementia. The centre will help to increase our knowledge within this field and generate more funding for such research, as the researchers will be able to compete for research funding nationally and internationally on a larger scale than before, and more patients will have the opportunity to participate in clinical trials.

### User participation in research and innovation

Patients with a brain disease or brain damage shall be heard, and this also applies to quality improvement, research and innovation. If patient experiences and their need for information is looked at in unison with the needs of researchers and health personnel, there is a greater chance that the treatment will be right for the target group. The Government has followed this up in its *white paper on pharmaceutical drugs* (Meld. St. 28 (2014-2015)), and in the National Health and Hospital Plan, and when following up the Health and Care 21 Strategy (HelseOmsorg21). Furthermore, the requirement of user participation has also been incorporated into the Norwegian Research Council's health programmes, and when announcing research funding at hospital trusts. The Norwegian Research Council's health programmes and the regional health authority programme for clinical research, use identified research needs as an instrument, as more priority is given to research aimed at the needs of users. Needs identified research is relevant when specific knowledge is required and user perspectives are important. The experiences of patients and relatives are important to obtain more information about the effects of coping initiatives. Common guidelines have been established for user participation at system level in the form of cooperation between the regional health authorities and the four regional user committees. All hospital trusts have a user committee. At the annual hospital trust meeting for 2016, the regional health

authorities were asked to establish youth councils, after which all the hospital trust established or are in the process of establishing such a council. Several examples of user participation are found in research, as well as in the development of guidelines and changed services. The new guidelines, *Knowledge-Based Guidelines for Epilepsy*, were

prepared by the Specialist Hospital for Epilepsy and represent the regional health authorities. The steering committee included a representative of the Norwegian Epilepsy Association. The Norwegian Multiple Sclerosis Association and users were involved in the development and establishment of the Multiple Sclerosis Registry.

## Welfare technology for better coping skills

Welfare technology helps users to independently cope at home, and it enhances their quality of life and confidence. It is important to map the needs and resources of users to obtain a complete picture when choosing welfare technology. Welfare technological solutions can help boost the confidence, coping skills and independency of users. Relatives can use such solutions as a supportive measure. In terms of the health service, welfare technology will release more time for care, give more sustainability and better services.

The national welfare technology programme consists of several projects aimed at different patient groups and diagnoses. One of the projects has tested some welfare technological tools for families with children with various functional impairments and diagnoses, such as cerebral palsy and ADHD. The purpose is to test welfare technological tools so that children and young people can participate in and master recreational activities, and to enable parents to more easily combine work with caring for their children. Regardless of the type of welfare technology tested by the families, the parents in the participating municipalities (Horten and Drammen) mainly had good experiences using technology as a participation and coping tool. Welfare technological solutions can help make it easier for children to socialise and engage in social contexts.

## Business developments and innovation

Medical technology and new drugs make it possible to treat more and more people in new and better ways. Business actors need to cooperate with the health and care services in connection with the testing and documentation of medical devices, welfare technology and pharmaceuticals. The regional health authorities will be commissioned to facilitate increased cooperation with the private sector in connection with the testing of medical-technical equipment and industry-financed clinical trials, etc.

A large proportion of new drugs and vaccines are researched and tested in cooperation with the pharmaceutical industry and health service. The innovation rate in the pharmaceutical industry is high. More than 7,000 substances are under development and less than 2,000 of these are for neurological and psychiatric disorders (Health Advances Analysis, 2015).

Nansen Neuroscience Network (NNN) is an innovation network that contributes to public-private sector cooperation between researchers and industrial actors for research and innovation for Parkinson's disease, Alzheimer's and other disorders associated with dementia and neurological diseases. NNN has been assigned the status of a national innovation network and has received funds from Innovation Norway.

Health and care services should increasingly facilitate innovation in public procurement. This is an instrument for developing solutions not currently on the market and which meet the needs of the services in a better way than today. Through innovation partnerships, Innovation Norway has funded a project titled, *A Stroke for the Future of Health Service*, initiated by C3 Centre for Connected Care (Oslo University Hospital), Sunnaas Hospital and the City of Oslo. The project will strengthen the interaction between new technologies and organisational innovation in the monitoring of stroke patients.

The health industry is an industry that can obtain double benefits, because it contributes to better welfare and health, and also creates growth and jobs. The Norwegian Parliament has decided that the Government shall submit a white paper on the health industry.

The white paper will also be significant to innovation and industry-developments within

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the field of brain health. Through a national e-health strategy, the Government will facilitate better access to health data and this will also apply to the private sector actors.

### **Health registries, quality improvement registries and national quality indicators**

Central health registries contain data on everyone treated by the health service. Health registries can be used to map the total burden and distribution of diseases, utilisation of health services within the population; and to investigate the relationship between risk factors and health outcomes and potential causes of diseases. Clinical quality improvement registries shall form the basis for quality improvement and research, but can also form the basis for statistics and health analyses, etc. The effects of treatment used in clinical practice can be documented in the quality improvement registries.

Analyses and research on treatment results recorded in the quality improvement registries form the basis for the quality assurance of clinical practice, reduce unwarranted variations and change clinical practice if the methods are not effective or safe. The quality improvement registries are increasingly being used as an alternative or adjunct to clinical trials to compare treatment results, and to form the basis for the recruitment of patients for clinical trials, especially when there are not many patients.

There are five national clinical quality improvement registries within the field of neurology: The Norwegian Parkinson's Disease Registry and Biobank, the Norwegian Multiple Sclerosis Registry and Biobank, the Norwegian Cerebral Palsy Registry, the Norwegian Registry for Hereditary and Congenital Neuromuscular Diseases and the Norwegian Registry for People Investigated for Cognitive Symptoms within the Specialist Health Service - NorKog. There is also a Norwegian Cerebral Stroke Registry, which is part of the National Cardiovascular Disease Registry. Statistics and results are published on the following web site: [www.kvalitetsregistre.no](http://www.kvalitetsregistre.no). The Norwegian Cerebral Stroke Registry provides data for ten national quality indicators on [helsenorge.no](http://helsenorge.no). The professional community has also initiated a quality improvement registry for ALS.

The regional health authorities are responsible for establishing and maintaining the clinical quality

improvement registries. The Norwegian Directorate of Health determines the national status of quality improvement registries.

The Norwegian Directorate of Health has determined which information is needed and where the quality improvement registries might be an relevant instrument. The regional health authorities have been asked to follow-up the Norwegian Directorate of Health's report and to jointly prepare a plan that shall include the management of areas with a low volume of patients and potential international cooperation under the auspices of the EU and Nordic countries.

The Norwegian Directorate of Health is responsible for developing, conveying and maintaining national quality indicators. The national quality indicators form the basis for the management, quality improvement and self-protection of patient rights. The national quality indicators give information about the structure, process and results of services. In combination they shall provide information about the overall quality of the selected sections of the health and care services.

### **Incorporate new information in basic, further and continuing education**

Excellent skills at the right level and in the right place are a prerequisite for good,

effective and safe health services. Consequently, it is a given fact that health personnel must update their skills to give the population equal access to services.

It is important that new research-based knowledge is appropriately incorporated into education programmes. The programmes have traditionally been governed in ways that have led to varying competencies depending on the educational institution. Educational programs have been static, and the services, users and health authorities have had little influence over the content.

The Norwegian Ministry of Education and Research has implemented a new steering system for foundation-level health and social education programmes at universities and university colleges.

The system is a more dynamic and comprehensive steering system, because the content of the programmes can be developed and updated regularly. Health services and other actors will have more influence on education. The system also contributes to a national standard for education programmes and variations between educational institutions with the same education programme are reduced. The new model for specialist education programmes for doctors emphasise measures that will strengthen

in accordance with the needs of the health service and patients.

Healthcare professionals must develop their competence after completing foundation-level education. Both employers and health personal are responsible for updating their skills and ensuring that training and further education meets the needs of the service.

The services are responsible for ensuring that health personnel receive the necessary training and further education. Health trusts contribute to skills development through continuing and further education programmes that target the needs of hospitals. The development of online courses, digital tools and e-learning options can improve cooperation between the hospitals. It can also help to coordinate the professional content of lessons. Good e-lessons can easily be shared and thus help introduce the best and uniform practices, regardless the treatment site.

The training must reflect the fact that health personnel shall work in teams and that expertise shall be gained through teamwork. Health personnel must acquire the skills to handle rapid medical and technological developments. Simulation as a teaching method is good for developing team and volume skills, and can help ensure equal competence and strengthen work on patient safety. The Norwegian network for simulation in the health service was established in 2016 with representatives from all the regional health authorities, to coordinate simulation activities within the health trusts.

In January 2017, the management and quality improvement regulations came into force. The regulations stress the importance of clear leadership, a culture of openness and learning, and a system to implement improvements. The regulations have provided managers throughout the health and care services with a tool that enables them to see which requirements they have to meet in order for the undertaking to deliver professionally viable health and care services.

### **Sub-objectives:**

- The Government has asked the Norwegian Research Council to announce the allocation of NOK 20 million for a clinical research centre in the form of a multiyear commitment to serious diseases of the central nervous system, for example, ALS, MS and dementia. In addition, research within the field will be strengthened with NOK 5 million.
- The experiences of users and their need for information will form the basis for improved quality, research and innovation.
- The Government will facilitate the development, testing and documentation of new solutions in collaboration with public health and care services, and the private sector.
- Develop several national quality indicators, especially indicators for treatment outcomes.
- Help ensure that the competence of graduates corresponds to a greater degree to the services and needs of users, and that a national standard of education is developed through the introduction of a new system for steering the learning outcomes of foundation-level health and social education programmes at universities and university colleges.
- Cooperate by exchanging e-learning lesson plans and health service simulation experiences.



## Overview of closely-related work

Meld. St. 19 (2014–2015) Folkehelsemeldingen – Mestring og muligheter (White paper on Public Health, Coping Skills and Opportunities).

Meld. St. 26 (2014–2015) Fremtidens primærhelsetjeneste – nærhet og helhet (White paper on Cohesion in Future Primary Health Services).

Meld. St. 11 (2015–2016) Nasjonal helse- og sykehusplan (2016–2019) (White paper for the National Health and Hospital Plan).

Meld. St. 34 (2015–2016) Verdier i pasientens helsetjeneste – Melding om prioritering (White paper on Values in Patient Healthcare. Notification of prioritisation).

NCD-strategy (2013-2017) (NCD Strategy). For the prevention, diagnosis, treatment and rehabilitation of four non-infectious common diseases; cardiovascular diseases, diabetes, COPD and cancer.

Helse Omsorg 21 (Health and Care 21). Knowledge promotion for better public health. A national research and innovation strategy, and the Government's action plan for following up the HelseOmsorg21 strategy.

Nasjonal strategi for EU Joint Programme – Neurodegenerative Disease Research (National Strategy for the EU's Joint Programme for Neurodegenerative Disease Research).

Mestre hele livet (Coping with all Aspects of Life). The Government's strategy for good mental health (2017-2022).

Strategi for sjeldne diagnoser (skal utarbeides)

(Strategy for rare diagnoses (to be prepared)).

Opptappingsplanen for rusfeltet (2016–2020)

(Substance Abuse Escalation Plan (2016-2020)).



Opptappingsplan for habilitering og rehabilitering (2017–2019) (Habilitation and Rehabilitation Escalation Plan (2017-2019)).

Opptappingsplan for barn- og unges psykiske helse (skal utarbeides) (Escalation Plan for the Mental Health of Children and Young People (to be prepared)).

Demensplan 2020 (Dementia Plan 2020). A more dementia-friendly society. Kompetanseløft 2020 (Competence Promotion 2020).

Nasjonalt handlingsplan for bedre kosthold (2017–2021) (National Action Plan for a Healthier Diet (2017-2021)).

NOU 2016 (Norwegian Official Report

2016:17): 17 Equality- Eight enhancements to realise the fundamental rights of the mentally handicapped.

NOU 2015 (Norwegian Official Report 2015:17): 17 First and foremost. A comprehensive system for managing acute diseases and injuries outside hospitals.

NOU om palliasjon (legges fram i slutten av 2017) (Norwegian Official Report on Palliative Care (to be presented at the end of 2017)).

NOU about priorities in the municipal health and care services (to be submitted by the end of 2018).

NOU om autisme og liknende diagnoser (arbeidet starter i 2018) (Norwegian Official Report on Autism and Similar Diagnoses (to be started in 2018)).

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