

Background Report to Updated Brain Health Strategy (2025-2035)

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Summary

The National Brain Health Strategy (2018-2024) was developed by the Ministry of Health and Care Services with contributions from the Norwegian Directorate of Health, the Norwegian Brain Council and a number of professional environments and user organisations. The strategy period ended in 2024 and the Directorate of Health was commissioned by the Ministry of Health and Care Services in the letter of allocation for that same year to prepare a draft version of an updated brain health strategy. The draft version will form the basis for the Ministry's final strategy, which is due to be launched in 2025.

This background report describes the insight process behind the drafting of the updated brain health strategy. The Directorate of Health has collated input from various stakeholders of relevance to brain health and pursued a dialogue with professional environments and user communities at both national and international level. Research, experience and knowledge concerning brain health from national and international sources have also been reviewed. The brain health strategy partnership was closely involved in the work. On behalf of the Directorate of Health, Oslo Economics conducted a review in 2024 of the status of the work on the national brain health strategy (2018-2024), in line with the assignment commissioned by the Ministry, which is also reproduced in this report.

The term 'brain health' relates to maintaining and enhancing brain function throughout life, including the ability to cope with life in spite of a brain disease. The term 'brain diseases' is used as a collective term to refer to diseases, injuries or conditions that affect the brain and the rest of the nervous system, including psychiatric and neurological diseases, as well as dependency disorders. The understanding of brain health and brain diseases has been continued from the previous strategy, but an attempt has been made in the draft updated strategy to provide more precise descriptions and to distinguish between them more clearly.

It is important that everyone has the best possible brain health throughout their lives, because brain diseases pose a significant public health problem and entail substantial societal costs. Many people become disabled and die from such diseases. No curative treatment is available for many brain diseases, so treatment will involve symptom relief. Although chronic conditions can vary in cause, symptoms and progression, common to them all is that they can significantly affect quality of life and require long-term treatment and follow-up. Comorbidity and multimorbidity are common and

can have a major impact on those affected, their relatives and society at large. To combat brain diseases, a better understanding of the brain will be needed, which in turn could lead to better treatment methods for such diseases.

As a result, it is important that the authorities implement measures that enhance the brain health of the population. Although not all brain diseases can be prevented, many can be avoided or reduced in severity and the authorities can do much to promote brain health throughout the population. Good brain health depends on both individual circumstances and the structure of society and requires health and care services to be available, safe and inclusive in order to support the population. Health-promoting and preventive measures are being implemented in every sector and the health and care services play an important role in cross-sector public health efforts and cooperation with other public, private and voluntary sector stakeholders.

Based on the insight set out in this background report, the Directorate of Health presents the following general recommendations concerning Norway's updated brain health strategy:

- **Ten-year strategy period:** The updated brain health strategy should have a duration of ten years, from 2025 to 2035.
- A holistic approach to brain health: The strategy should have a holistic approach that encompasses a broad range of brain diseases and addresses shared needs and challenges.
- Continue the primary objectives from the previous brain health strategy: The four primary objectives of the previous strategy are considered to be appropriate and comprehensive.
- Fewer and clearer sub-objectives: The strategy should have fewer and clearer sub-objectives, while there should also be scope for different approaches and measures in order to achieve them.
- Action plan after launch of the strategy: In the follow-up to the strategy, an action plan should be prepared as an initial step. This action plan should contain specific measures to achieve the sub-objectives and include a schedule, delegation of responsibilities and criteria for achievement of the objectives, in addition to evaluation methods.
- Status reporting in the work on the strategy: A concise status update should be prepared at regular intervals during the work relating to the updated brain health strategy.
- Midway evaluation: An evaluation midway through the strategy period is important in order to assess progress, identify challenges and adjust measures to ensure that the sub-objectives are achieved.
- **Specific objectives for brain health:** The sub-objectives should address needs that are not covered by existing strategies and initiatives.
- Experiences at national and international level: The strategy should look at experiences gained within other areas of health and disease, as well as similar work in other countries.
- Communication document with a strong educational approach: The strategy should be educational, with a clear message and a clear direction.
- Collaboration and dialogue with relevant stakeholders: Maintain collaboration with the
 partnership and other stakeholders to obtain insight into challenges and possible solutions,
 among other things.

Background and process

The brain is the most complex organ in the human body and enables people to sense, feel, think, move and interact with the world around them. It is important to preserve and develop the brain in order to achieve good health throughout an individual's life course (Wang et al., 2020; World Health Organization, 2022). Brain health is important for good health in general, quality of life, productivity and creativity throughout life. It is a question not only of avoiding illness, but also of safeguarding the cognitive, emotional, behavioural and social functions that help a person to cope with different life situations (Bassetti et al., 2022).

A high proportion of Norway's population will be affected by brain diseases during their lifetime (Ministry of Health and Care Services, 2017; Nordengen, 2020) and a significant number of people die as a result of a brain disease. Many people have functional impairments and face barriers to participating in society. No curative treatment is currently available for many brain diseases, only symptom relief. People with brain diseases also often suffer from chronic ailments which they have to live with for many years (Boon et al., 2025). These conditions can vary in cause, symptoms and progression, but common to them all is that they can significantly affect quality of life and require long-term treatment and follow-up (Steinmetz et al, 2024). We also do not know enough about what causes many brain diseases (Ministry of Health and Care Services, 2017).

The relatives of someone with a brain disease can face varying health challenges. Worries, care tasks and support from relief agencies can affect how individual relatives perceive the burden (Pårørendesenteret, 2017).

In order to provide good care, treatment and tailored follow-up to people suffering from brain diseases and support their relatives, close cooperation between the various levels of the health and care services is crucial. This is because many people with a brain disease are in need of extensive help and follow-up from both the municipal health and care services and the specialist health service (Ministry of Health and Care Services, 2017).

The authorities can do much to promote the best possible brain health among the entire population and ensure follow-up and treatment for those with a brain disease. Brain health is arguably one of the biggest global health challenges of the 21st century (Dawson et al., 2020). Building the foundations for the best possible brain health for everyone is therefore the most valuable investment a society can make (Aivoliitto, 2022a; Hachinski & Ganten, undated). A brain health strategy is therefore important.

National Brain Health Strategy (2018-2024)

In December 2017, the Ministry of Health and Care Services launched the National Brain Health Strategy (2018-2024) (Norwegian Government, 2017). This strategy was developed with input from the Directorate of Health, the Norwegian Brain Council and many professional environments and user organisations (Ministry of Health and Care Services, 2017). The timeframe for the national brain health strategy covered the period from 2018 through to 2024 inclusive.

The strategy was to provide direction within prevention, health promotion measures, investigation, treatment, habilitation, rehabilitation and research and innovation. The brain health strategy aimed

to ensure appropriate investigation, adequate treatment and facilitated follow-up of users and patients, while safeguarding the interests of relatives. The strategy set out goals, provided direction to achieve them and served as a foundation for political decisions and actions. The main focus was placed on the responsibilities of the municipal health and care services and the specialist health service. The strategy also highlighted the ability of individuals to enhance their own brain health and cope with life with limited functional capacity due to a brain disease (ibid.).

The National Brain Health Strategy (2018-2024) was the first political strategy concerning brain health to be launched anywhere in the world (Norwegian Government, 2023). Internationally, more and more people are becoming aware of the Norwegian brain health strategy and interested in the experiences that Norway has gained (Aamodt et al., 2024; Avan et al., 2023; Bassetti et al., 2022; Chen et al. 2021; Fundacja NeuroPozytywni, 2019; Hachinski et al., 2024; Hjärnfonden, 2023b; World Health Organization, 2022).

The brain health strategy had four primary objectives and a total of 29 sub-objectives. The four primary objectives of the strategy were:

- 1. Good lifelong brain health, prevention and quality of life
- 2. Health and care services that are more user-centred and take better care of relatives
- 3. Good care from the onset of symptoms to diagnosis, treatment, habilitation and rehabilitation
- 4. Adequate knowledge and quality through research and innovation

Assignment to prepare a draft updated brain health strategy

In the summer of 2023, the Ministry of Health and Care Services announced that it would present a new and updated brain health strategy in 2025 (Norwegian Government, 2023). In 2024, the Directorate of Health was therefore commissioned by the Ministry to draft an updated strategy, with the following remit:

"The Directorate of Health is asked to prepare a draft version of an updated brain health strategy. Although the draft will primarily build on existing overarching objectives, it may be necessary to develop new sub-objectives. Reference is made to the Public Health Report, the Escalation Plan for Mental Health and the National Health and Coordination Plan (2024) as a basis for the Government's health and care policy. The Directorate is asked to determine the status of the brain health field as a basis for the update, so that an updated strategy also presents the results that have been achieved through the work to date. The partnership and other relevant stakeholders shall be involved in the process." (Ministry of Health and Care Services, 2024a, p. 23, assignment TB2024-47).

The Directorate of Health's assignment was continued with somewhat similar wording in the letter of allocation from the Ministry of Health and Care Services in 2025 (Ministry of Health and Care Services, 2025, p. 28, assignment TB2025-40).

This document ('the background report') aims to provide the Ministry of Health and Care Services with an updated knowledge base for the design of the updated brain health strategy that is to be launched in 2025. The background report describes the process for obtaining insight and other information that will form a basis for the work of the Directorate of Health in drafting the updated brain health strategy. The Directorate of Health's proposed sub-objectives are included in the draft

updated brain health strategy and not in this document. The draft updated brain health strategy will hereinafter be referred to as 'the draft'.

The national brain health strategy for the period 2018 to 2024 primarily focused on the responsibilities of the health and care services. At the same time, the brain health of the population is also promoted in the various arenas in which individuals spend and live their lives, such as at home, school or the workplace, or during their leisure time. The Directorate of Health has interpreted the task of drafting a new strategy as involving an *update* to the previous strategy, in line with the wording of the assignment and the dialogue with the Ministry. The principal orientation in the previous strategy has therefore been retained, with the consequence that the updated strategy is also not cross-sectoral.

United around the brain: Pivotal stakeholders in the work

The work relating to the background report and draft was organised in project form, with a project owner, project group and steering group. Brain health is a broad and extensive field and many people are affected by brain diseases or involved in brain health in different ways. As a result, the project organisation also included a partnership consisting of various stakeholders. In addition, a working group was created to assist in the work to draft the updated brain health strategy.

The Directorate of Health has received input and experienced considerable engagement from individuals, user organisations and the health and care services, as well as professional environments, both nationally and internationally. The dialogue with the stakeholders involved was crucial for a holistic and inclusive approach in the work to draft the updated brain health strategy. The Directorate of Health would like to thank everyone who contributed valuable knowledge and engagement in the work.

Project group

The project was anchored in the specialist health service's department of professional development within the Directorate of Health and consisted of a project group which coordinated the work and drafted an updated brain health strategy and associated background report.

Project group composition

Name Role

Silja Nicoline Angellsen Project manager

Kristiane Bugge Dugstad Project group member

Kaja Fjell Jørgensen Project group member

Partnership

The partnership consists of stakeholders invited by the Directorate of Health. It performed an advisory function in the work on the brain health strategy. The partnership will be a driving force in the work relating to the brain health strategy, by promoting new ideas and creating dialogue and collaboration. This is being done by the participants bringing up challenges and discussing possible solutions within the work on brain health.

The participants represent user organisations, the specialist health service, the municipal health and care services and other relevant professional environments.

Representatives in the National Brain Health Strategy partnership

Organisation	Name
	Henrik Peersen
Norwegian Brain Council (hjerneradet.no)	Magne Wang Fredriksen
	John Stigum
FFO (ffo.no) (Norwegian Federation of Organisations of Disabled People)	Eva Buschmann
SAFO (safo.no) (Norwegian Forum of Disabled Peoples' Organizations)	Grethe Müller
Norwegian College of General Practice (legeforeningen.no)	Marte Kvittum Tangen
South-Eastern Norway Regional Health Authority (helse-sorost.no)	Trude Hirgum Jahren
Western Norway Regional Health Authority (helse-vest.no)	Anette Storstein
KS (ks.no) (Norwegian Association of Local and Regional Authorities),	Anne Gamme
City of Oslo, Agency for Health (oslo.kommune.no)	Hilde Therese Katralen

Ingrid Thunem

Expert Panel for Neurology Nursing (nsf.no)

Annbjørg Hausken

The various stakeholders in the partnership will work together to contribute to the implementation of measures, but the established responsibilities, authorities and reporting lines of the participants will not change in any way.

The collaboration between the Directorate of Health and the partnership is a vital key component in the work on the brain health strategy. It will therefore be crucial to maintain the partnership in the follow-up to the updated brain health strategy. At the same time, it will be natural to conduct an evaluation of how the partnership has worked, its organisation and the composition of stakeholders.

Working group

The working group consisted of representatives from various departments and divisions within the Directorate of Health of relevance to brain health and brain diseases. The working group also included a representative from the Norwegian Brain Council.

The working group's mandate was to ensure that the content of the background report and the draft was in line with ongoing and existing assignments, measures and work of relevance to brain health. The working group was also tasked with providing specialist advice to the project team. As and when appropriate, the members of the working group submitted written contributions to the background report and draft within their respective disciplines. In addition, the involvement of the Norwegian Brain Council was intended to ensure user participation. The participant from the Norwegian Brain Council did not have access to written input from the other members of the working group. This ensured that the process was conducted in an orderly manner and avoided role-related conflicts.

Obtaining insight

The Directorate of Health has used various methods to acquire knowledge about the current situation within brain health and to identify the appropriate and desired direction for future efforts in the field. The dialogue with relevant individuals, businesses and organisations provided a sound basis in the work to prepare the background report and draft.

Invitation to submit input concerning the draft updated brain health strategy

The Directorate of Health ensured that stakeholders of relevance to brain health were able to submit input from different perspectives. Stakeholders who provided input are referred to as "the

stakeholders". The Directorate of Health invited stakeholders to attend various arenas in order to submit their written input concerning the updated brain health strategy. The various arenas are listed in chronological order:

Consultation conference

The Directorate of Health held a digital consultation conference on 6 June 2024; see Appendix 1. The 55 registered delegates were divided into groups with varied composition, based on specific criteria, including place of residence and representation from different organisations and levels within the health and care services. The purpose of this division into groups was primarily to encourage discussions with different perspectives that could support or harmonise with the needs and objectives of other organisations or enterprises. The consultation conference was primarily divided into four parts, each linked to one of the four main objectives of the strategy. The seven groups were each assigned predefined questions, associated with each primary objective; see Appendix 2. These questions were prepared in a dialogue between the project team, the working group and the partnership. The groups discussed and recorded input, which they then submitted to the Directorate of Health via an electronic form.

Consultation round

Following the consultation conference, the Directorate of Health invited further contributions to the updated brain health strategy; see Appendix 3. From 6 to 20 June, individuals and organisations of relevance to brain health and brain diseases were given the opportunity to share their views and submit written suggestions concerning the updated brain health strategy to the Directorate. This opportunity to contribute input ('the consultation round') did not require any pre-prepared questions from the Directorate of Health. This gave participants the freedom to focus on self-selected topics. In total, input was received from 17 different stakeholders.

Consultation process within the Directorate of Health

Relevant departments within the Directorate of Health were invited to provide feedback on the background report and the draft. The internal consultation period within the Directorate extended from 19 September to 11 October 2024.

Round table meetings organised by the Norwegian Brain Council

In May 2024, the Norwegian Brain Council (hjerneradet.no) organised two one-day meetings for its member organisations, which at the time consisted of 77 organisations. The aim was to explore challenges and solutions relating to brain health and brain diseases and to assess preferred sub-objectives for the impending brain health strategy. The first session, held on 14 May, concentrated on objective 1 (prevention and quality of life) and objective 4 (knowledge and quality). The second session, held on 27 May, addressed objective 2 (user involvement and support for relatives) and objective 3 (good care pathways). The Norwegian Brain Council collated and processed the feedback from members and forwarded it to the Directorate of Health; see Appendix 10.

Political guidelines

The Directorate has looked at national strategies and action plans within coincident fields of health and disease. This was done in order to gain an insight into possible common challenges and solutions and political guidelines, as well as to draw inspiration for a strong educational approach to the draft.

In the work, the following national strategies and action plans were taken into account:

- National Strategy for Rare Diagnoses (regjeringen.no)
- National Alcohol Strategy (regieringen.no) 2021-2025
- National Action Plan for Clinical Studies (regjeringen.no) 2021-2025
- The Norwegian Government's next of kin strategy and action plan (regjeringen.no)
- Action Plan on Physical Activity 2020-2029 (regjeringen.no)
- Dementia Plan (regjeringen.no) 2025
- Competence Lift (regjeringen.no) 2025
- National Strategy for Personalised Medicine (regieringen.no) 2023-2030
- The Norwegian Government's Women's Health Strategy (regjeringen.no)
- National Cancer Strategy (regieringen.no) 2025–2035
- Norway's Action Plan for Sustainable Development and Equal Opportunities (regjeringen.no) 2021-2025
- Action Plan for Suicide Prevention (regjeringen.no) 2020-2025
- The Norwegian Government's action plan for the equality of persons with disabilities (regjeringen.no) 2020-2025
- Strategy to improve health literacy in the population (regjeringen.no) (2019-2023)
- National Brain Health Strategy (regjeringen.no) (2018-2024)

The Directorate of Health has also reviewed reports to the Storting, where the Government's political guidelines were used as a basis in the preparation of the sub-objectives in the draft.

- Prevention and treatment reform for the area of substance abuse (<u>Meld. St. 5 (2024-)</u> (<u>regjeringen.no</u>))
- Long-term plan for research and higher education (Meld. St. 5 (2023-2032) (regieringen.no))
- National Health and Collaboration Plan (Meld. St. 9 (2023-2024) (regieringen.no))
- Report on quality and patient safety (Meld. St. 11 (2020-2021) (regieringen.no))
- Public Health Report (Meld. St. 15 (2022-2023) (regjeringen.no))
- Escalation plan for mental health (Meld. St. 23 (2022-2023) (regieringen.no))
- The safe home reform (Meld. St. 24 (2022-2023) (regieringen.no))
- The equality reform (Meld. St. 25 (2020-2021) (regieringen.no))
- Action plan to achieve the sustainable development goals (Meld. St. 40 (2020 2021) (regjeringen.no))

Other insight into the work

The Directorate of Health also searched databases and websites to collate relevant research and knowledge relating to brain health, from both national and international sources. The Directorate of Health invited professionals and organisations from Norway and elsewhere to exchange experiences relating to brain health. The decision on who to contact was based on suggestions from other stakeholders and searches in databases and elsewhere on the internet.

In the assignment given to the Directorate of Health by the Ministry of Health and Care Services, the Directorate was asked to provide a status update within the field of brain health. The twin aims

of this status update were to ensure that the updated strategy reflects the progress that has been made and to identify areas that still require attention (Ministry of Health and Care Services, 2024a, p.23, assignment TB2024-47). Based on this, the Directorate of Health commissioned Oslo Economics to map the work relating to the brain health strategy from 2018-2024. This mapping is discussed further in Chapter 4.

Public consultation

The Directorate of Health made the draft and background report available for public consultation via the Directorate's website and also distributed the documents directly to relevant parties. The public consultation period extended from 8 November 2024 to 30 January 2025. The Directorate of Health received 46 responses from individuals and organisations. All input has been collated and structured into chapters in a single document, which is attached. All input received from individual stakeholders is also attached. See Appendix 11 for additional information.

Brain health

The brain – our irreplaceable and most complex organ

The brain is both irreplaceable and one of the most complex and fascinating organs in the human body. The brain consists of approximately 100 billion nerve cells, which create around 100,000 billion synapses, the connections between the nerve cells (Gorelick & Sorond, 2024; Tran, 2022). The more synapses in the brain, the easier it is to adapt to new challenges. In order for the brain to create more synapses, it is necessary to learn new things (Nordengen, 2020). Brain development is often described as consisting of three stages throughout the life course. These stages are neuroplasticity, pruning and neuronal loss, which collectively express the lifelong adaptation of the brain (Patel et al., 2018).

Neuroplasticity involves the brain forming new neural connections and strengthening synapses between neurons throughout a person's life (Cherry, 2024). The brain has an innate ability to adapt by altering the connections between nerves and brain cells based on behaviour, environment and experiences. Pruning is the process by which the brain removes neurons and synapses that it does not need. This occurs mainly during the age range 2-10 years (Rowden, 2023). Neuronal loss concerns the loss of nerve cells during adulthood (University of Barcelona, 2024). The loss of nerve cells will affect brain function and health.

Although it was previously believed that these three stages followed each other without any overlap, it is now known that the brain can continue to develop and adapt, even as it ages. Because of neuroplasticity, brain health can therefore be promoted throughout life by reducing risk factors and strengthening protective factors (World Health Organization, 2022).

What is brain health?

In 1948, the World Health Organization (WHO) defined the term 'health' to mean not only the absence of disease, but also the presence of physical, mental and social well-being (World Health Organization, 1948). The term 'brain health' was first introduced in research literature in 1989 (Chen et al., 2021). The term was rarely used until 2011, but it saw a marked upturn in the literature in 2017, followed by a further upsurge the following year (World Health Organization, 2022).

The term 'brain health' was first introduced in Norway by the Norwegian Brain Council in 2015 (Norwegian Brain Council, undated). The term then received more attention after the Directorate of Health launched a status report on brain health in 2017 on behalf of the Ministry of Health and Care Services (Directorate of Health, 2017). In the same year, the National Brain Health Strategy was launched, further strengthening the focus on the concept of brain health.

Over the years, there has been extensive discussion about what should be included in the term 'brain health' (Owolabi et al., 2023) and both organisations and professionals have used different definitions (Chen et al., 2021; Gorelick et al., 2017; Hendrie et al., 2006; Wang et al., 2020). Although use of the term has varied, the different definitions have certain commonalities (The Lancet Neurology, 2022).

Hachinski et al. (2021) refer to brain health as a state of complete physical, mental and social well-being achieved through continuous brain development and exercise. The World Health Organization describes brain health as being the state of brain functioning across cognitive, sensory, social-emotional, behavioural and motor domains, allowing a person to realise their full potential over their life course, irrespective of the presence or absence of disorders (World Health Organization, 2022). Chen et al. (2021) refer to brain health as the complete functioning of the brain throughout its life cycle, which is supported by physical, mental, social and spiritual well-being and quality of life.

Gorelick & Sorond (2024) explore various definitions of the term 'brain health' and identify a number of core features:

- the entire life course is included, not just a particular phase
- preservation of brain structure and function is essential
- brain health is affected by factors such as environment, genes and interactions
- many risk factors for brain health can be changed
- brain health is promoted through global collaboration between science, public health policy and political priorities

In Norway, brain health is considered to be a comprehensive term that revolves around maintaining and enhancing brain health throughout life. The term includes the overall state of the brain's functions, such as cognition, senses, emotions and movements, regardless of whether brain diseases are present or absent (World Health Organization, 2022). Brain health is also about each individual person's ability to promote their own brain health and cope with life despite brain disease (Ministry of Health and Care Services, 2017).

Why a strategy for brain health?

Everyone has brain health and a significant proportion of people are affected by brain disorders (Norwegian Government, 2023). If relatives are included, most of the population of Norway is probably affected by brain disorders. It is therefore important to raise awareness of brain health and prioritise it, not only at individual level, but also at system level and societal level. This awareness will be particularly important going forward, given demographic trends such as increased life expectancy (Avan & Hachinski, 2024). According to the World Health Organization (2023b), to make real progress in improving brain health for all, the term 'brain health' must be included in public health strategies and policies. It is therefore essential that Norway has a national brain health strategy.

There are various models which show how the brain and brain health are affected throughout life, thus illustrating action areas for promoting brain health.

Sabayan et al. (2023) state that brain health is affected through three mechanisms: (1) damage (exposure to risk factors), (2) resistance to damage (active repair) and (3) inherent functional resilience (ability to adapt to adversity/damage). The model emphasises the necessity of prevention strategies aimed at the entire life course and includes protecting the brain from damage that the brain itself is unable to repair.

The model that Bassetti et al. (2022) refer to can be viewed in conjunction with the mechanisms explained by Sabayan et al. (2023), but includes factors that can promote or protect brain health to a greater extent. The model categorises factors that affect the brain and brain health into three levels: (1) preserving – promoting factors linked to an individual's mental and physical activity; (2) protecting and preventing – reducing risk factors; and (3) planning – factors at societal level that must be addressed by decision-makers.

Protective factors for brain health

At a general level, a healthy lifestyle is beneficial to the health of the brain. According to the World Health Organization (WHO), health promotion is a process that allows individuals to gain better control over and improve their own health (World Health Organization, 1998). Promoting brain health is about improving and maintaining brain function and well-being throughout life (ibid.). Looking after the brain throughout life can provide significant benefits and enable people to preserve important abilities, even when faced with brain disease (DeCarli, 2018). Factors that can help preserve good brain health include social contact, reducing mental stress, a healthy diet and protecting the head from injury (Bassetti et al., 2022). Sleep is another factor that is important for promoting brain health (Bassetti et al., 2022; Lewis, 2021).

Physical activity is also an important factor in promoting brain health (Bassetti et al., 2022; Tari et al., 2025). A systematic umbrella review and meta-meta analysis by Singh et al. (2025) indicates that physical activity and movement can have positive effects on general cognition, memory and executive function (which is a collective term for, among other things, problem-solving ability, planning and self-regulation of behavior). The brain is probably the organ that is most affected by physical activity (Hjelle, 2018). Wisløff and Tari (2025) argue that physical activity accounts for about 50% of the positive health effects achieved through a healthy lifestyle. They point out that, despite this, about 97% of health budgets in Norway are spent on treating diseases, while only 3% are used for preventive measures (ibid.).

Risk factors for brain health

Preventing brain diseases is about reducing the risk of developing disease, identifying signs of disease and challenges and preventing, delaying or reducing the consequences of disease (Gammersvik & Larsen, 2018). Repeated alcohol consumption is an example of a risk factor for brain diseases (Singh et al., 2025b). Reducing or avoiding drug consumption, especially during adolescence, is therefore important for promoting brain health (Chikritzhs et al., 2024). Other possible risk factors include high blood pressure and cholesterol (Aamodt et al. 2024). Limiting risk factors for brain diseases can also have a positive impact on other diseases, such as heart disease (ibid.).

Lack of sufficient good-quality sleep is another risk factor for developing brain diseases (Palma et al., 2013). Adolescents in particular do not appear to get enough sleep (Saxvig et al., 2021). Evanger et al. (2024) conducted a longitudinal study concerning the relationship between sleep patterns, sleep difficulties, depression, anxiety and academic grades among students at a sample of upper secondary schools in Norway. The results of the study indicated that there was a correlation between shorter sleep duration on school days and lower average grades, irrespective of symptoms of depression and anxiety (ibid.). The results may indicate that sleep is crucial for adolescent brain health.

There is increasing evidence to suggest that air pollution could have an impact on the incidence of certain brain diseases (Aamodt et al. 2024; Huang et al., 2025; Wilker et al., 2023). Other important factors include avoiding pollutants and living healthily during pregnancy in order to provide good conditions for good brain health. People should also avoid smoking and maintain a healthy weight. Risk factors for some brain diseases may also be linked to impaired vision and hearing loss (World Health Organization, 2022). A Norwegian study by Myrstad et al. (2025) shows a link between impaired hearing and cognitive impairment. The study concludes that the early treatment of hearing loss may be crucial in reducing the risk of cognitive impairment.

The impact of risk factors can build up over time, eventually becoming too much for the brain's repair mechanisms to cope with, leading to physical and functional changes in the brain (Sabayan et al., 2023). In turn, these changes can lead to symptoms and irreparable deterioration of brain function (ibid.). To prevent brain diseases, initiatives should be targeted at all three levels of prevention. These are as follows: 1) primary prevention, which is the prevention of brain diseases occurring, 2) secondary prevention, which is the prevention of new events or deterioration and finally, 3) tertiary prevention. Tertiary prevention is about maintaining the best possible function and quality of life in the event of brain disease and preventing the condition from becoming more severe.

Brain health from a gender perspective

Women can experience different symptoms of brain disease compared with men (Ministry of Health and Care Services, 2024b). Studies show that hormones shape women's brain health and risk of developing brain diseases throughout their lives. It is therefore important to understand the complex interaction between risk factors and protective factors for women's brain health (Barth et al., 2023; de Lange et al., 2020).

There are also knowledge gaps regarding the health challenges that men face, their causes and how brain health can be improved. Men do not live as long as women and are over-represented in

risk factors such as smoking, alcohol consumption, poor diet, inactivity, obesity and high blood pressure. These risk factors affect the incidence of brain diseases and other non-communicable diseases (NOU 2024:8).

Socioeconomic status and brain health

A study of socioeconomic status and brain health found that people with higher socioeconomic status throughout life had better cognitive function (Krueger et al., 2025). This is consistent with other studies which show that resources in both childhood and adulthood are important for brain health (ibid.).

Hamza et al. (2024) also believe that low socioeconomic status, and poverty in particular, can lead to poor nutrition, high stress levels in caregivers and children and exposure to high-risk environments. These factors can harm the development of the brain, which in turn can lead to mental health problems and poorer performance at school. This can create a "vicious cycle", in which children with low socioeconomic status who grow up in poverty continue to experience poverty and health problems in adulthood. To break this cycle, Hamza et al. (2024) believe that financial support alone will not be sufficient. It is also important to target measures at improving brain health and development in children from families with low socioeconomic status and poverty (ibid.).

Farah (2018) notes that our understanding of how socioeconomic status affects the brain is still limited. Many questions remain, such as which findings will be valid over time and which mechanisms link socioeconomic status to the brain. It is also unclear whether these findings depend on specific factors such as income or neighbourhood, or whether there are other causes (ibid.).

In order to address differences in brain health, it is important to understand the relationship between socioeconomic status and brain health (Hamza et al., 2024; Krueger et al., 2025).

Brain health at system level

Societal planning can help promote brain health among the entire population. Contextual factors such as the environment in which a person lives, security, what they learn throughout life and what services they have access to also affect brain health. Facilitating and planning at societal level are important because brain health is affected by health determinants (in other words, impactors on health, such as income and education), which in turn creates social inequalities in health, including brain health (Hilal & Brayne, 2022). Risk factors can increase gradually from early in life and lead to differences in brain health through life (ibid.). Brain health thus becomes a shared responsibility across sectors, requiring a holistic approach in which both individual and societal factors throughout life are taken into account.

Among other things, the health and care services are responsible for treating, preventing and facilitating the management of illness, injury, suffering and disability. These services have also been tasked with contributing to cross-sector public health work and cooperating with other public, private and voluntary sector stakeholders. Although the brain health strategy is specifically aimed at the health and care services, it should be noted that health-promoting and preventive measures are being implemented in all sectors.

Health behaviour and lifestyles are greatly influenced by socially created conditions for good health. Public health measures should be designed to even out social health inequalities. Universal and

structural measures such as economic instruments and regulations appear to have a positive impact on improving public health in a way that evens out social health inequalities (Meld. St. 15 (2022-2023)).

Türken et al. (2024) note that health-promoting measures should be communicated in a way that does not make the population feel guilty if they do not make good lifestyle choices or implement measures to promote brain health. It is important to recognise that major societal and economic factors also come into play. Those in need should get help and guidance to understand and change their lifestyle choices, ideally in collaboration with others (ibid.).

Universal design is an important prerequisite for good brain health, because it enables activity and mastery to feel safe and readily available (Ministry of Culture, 2021). Good planning is about enabling everyone to participate, regardless of functional capacity or injury.

The relational model of impairment views health as a product of the interaction between individual circumstances and societal needs. The model stresses that brain health is not only about the presence or absence of brain diseases, but also the structure of society. By removing barriers and creating inclusive environments, the brain health of everyone in the population can be supported. The health and care services must be available at the right time and place and to an appropriate extent. Furthermore, the services must be provided in a safe manner, which entails minimising the risk of injury and promoting positive health outcomes (NOU 2016:17, 2016).

Universal design can remove barriers and structure society in a way that is accessible for everyone, regardless of their functional capacity (ibid.). This is especially important as many brain diseases can affect a person's ability to, for example, inform themselves, interact with their environment, perform work and participate in democratic processes (Strand et al., 2021).

It is important to be conscious of promoting positive attitudes and increasing social awareness of people with functional impairments, as well as respecting their rights and dignity. This is part of Norway's obligations under the Convention on the Rights of Persons with Disabilities (CRPD), which is to be incorporated into Norwegian law.

Good brain capital – an important investment

A healthy lifestyle can help prevent or reduce the risk of brain diseases (Bassetti et al., 2022; Clocchiatti-Tuozzo et al., 2024; Hachinski et al., 2024), symptom burden and functional impairment. Looking after brain health does not simply help to reduce health costs by promoting overall health and reducing the incidence of chronic health problems associated with brain diseases. It also offers significant societal and economic benefits throughout life. Good brain capital is therefore crucial for brain function, both for every individual and for society as a whole (World Health Organization, 2022). The term 'brain capital' is about prioritising brain health and making it an important part of how progress and prosperity are measured in society. This will enable a stronger and more resilient society to be built (Eyre et al., 2021).

Brain diseases

Brain diseases represent a significant proportion of the diseases that occur in Norway. They affect a large number of people and can have serious consequences (Oslo Economics, 2024).

What are brain diseases?

Brain diseases include psychiatric and neurological diseases, conditions and injuries (Ministry of Health and Care Services, 2017; Olesen et al., 2011; Wang et al., 2020). Dependency disorders are also included (Ministry of Health and Care Services, 2017; National Institute on Drug Abuse, undated). Brain diseases can either arise or develop during life, or they can be congenital. They are characterised by disorders of brain development, damage to brain structure and/or impaired brain function (Wang et al. 2020).

The term 'brain diseases' is hereinafter used to refer to diseases, conditions and injuries that affect the brain and the rest of the nervous system.

Brain diseases can be acute, progressive or chronic. Some people can experience an absence of symptoms, either completely or during certain periods of time, while others have to live with major health challenges (Ministry of Health and Care Services, 2017). Some brain diseases can also occur in the form of seizures, which can make them difficult to predict and manage.

Certain diseases develop throughout the life course due to the impact of lifestyle choices and the environment, in interaction with genetic predisposition (Polderman et al., 2015). 'Genetic predisposition' refers to an increase in the probability of developing certain brain diseases based on inherited genes (Smeland et al., 2023). Other diseases may be congenital and present from birth, caused by genetic or developmental factors.

One particular challenge for people with a brain disease is that it can lead to impaired cognitive function and personality changes. This is often challenging for both the person concerned and their relatives (Ministry of Health and Care Services, 2017).

Comorbidity in brain diseases

Individuals who have one or more brain diseases, a combination of other diseases and/or other health challenges, represent a growing global challenge with a major impact on individuals, relatives and society (Skou et al., 2022).

A study by Barnet et al. (2012) showed that most people with chronic diseases have at least two, and often more, other disorders. The number of diseases and the proportion of people with comorbidity increase significantly with age (ibid.). It is well-known that comorbidity in brain disease is common. Comorbid conditions increase the disease burden and can make it challenging to provide effective treatment (Hesdorffer, 2016).

Drug disorders often occur in conjunction with mental disorders (Long et al., 2017; Torvik et al., 2018). Patients who are treated for a substance abuse disorder often have one or more concomitant mental disorders (Beard et al., 2016). Drug problems can develop as a consequence of mental health problems, but the reverse can also be true (Chassin et al., 2013).

According to Demarin & Morovic (2021), the degree of comorbidity between mental and neurological diseases is high and patients are often under-assessed or misdiagnosed.

Helsebiblioteket (2020) refers to the World Health Organization, which claims that premature death and disease as a result of brain diseases can be reduced by devoting more attention to comorbidity.

Common biology and risk factors between mental and neurological disorders

There are numerous types of brain disease. Some have a clear cause in the brain and this is the type that is most often recognised. However, a broader view recognises that there are other ways of developing a brain disease, other than just those with a clear cause in the brain (Jefferson, 2022).

One particular challenge is the management of comorbidity between mental and neurological disorders. This is because the treatment of these disease groups is primarily organised into different disciplines (neurology and psychiatry), which are today characterised by both separate specialisation and separate professional environments. Ibanez & Zimmer (2023) highlight the close link between psychiatry and neurology in terms of brain health. The two categories have common genetic and environmental factors, as well as common lifestyle factors, which can contribute to psychiatric and neurological diseases. A broader interdisciplinary and integrated approach can help understand, prevent and treat brain diseases and develop sound methods for research, prevention and intervention (ibid.).

A recent major genetic study conducted at Oslo University Hospital (Smeland et al., 2023) showed that there is no sharp genetic distinction between neurological and mental disorders, as was previously thought. However, the study also shows that neurological and mental disorders largely share genetic risk and biology linked to the brain. The findings are consistent with the high level of comorbidity between the conditions and suggest that many individuals will have an elevated genetic vulnerability to both mental and neurological disorders. The study thus supports recent research (Ibanez & Zimmer, 2023) which suggests that mental and neurological disorders are more closely associated than is indicated by the traditional delimitation between disease groups.

Although there are many different neurological and psychiatric diagnoses, they have a number of key commonalities. An understanding of the links between psychiatry and neurology could lead to better treatment for diseases affecting the brain (Institute of Medicine, 2001).

When the Directorate of Health prepared the status report on brain health in 2017 (Directorate of Health, 2017), there was some disagreement regarding the definition of the term 'brain health' and whether mental disorders should be included. However, the Ministry of Health and Care Services decided that neuropsychiatry and mental disorders with presumed central biological causes should be included in the brain health strategy for 2018-2024. Although there still seem to be differing opinions on this issue, the Directorate of Health opted to follow the decision by the Ministry of Health and Care Services when formulating the draft updated brain health strategy.

Disease burden and disability as a result of brain diseases

Brain diseases account for as much disease burden as cancers (16%) and cardiovascular diseases (10%) combined (Norwegian Brain Council, 2021, p.15). Norway does not have sufficient

knowledge of the overall disease burden caused by brain diseases, because international and national health statistics on brain diseases are spread across different categories. However, calculations by the Global Burden of Disease Study indicate that the disease burden (Disability-Adjusted Life-Years or DALY) caused by brain diseases in Norway in 2021 amounted to 29% (Institute for Health Metrics and Evaluation (IHME), 2024; Ann Kristin Skrindo Knudsen, Henrik Peersen & Lars Jacob Stovner, personal communication, 30 March 2025). Years of Life Lost (YLL) as a result of brain diseases amounted to 22%, while Years Lived with Disability (YLD) amounted to 36% in Norway in 2021 (ibid.).

Incidence: One in three people in Norway will develop a brain disease during their lifetime

In Norway, there is a limited overview of the disease burden arising from brain diseases and there are few collated statistics for the area. The figures presented in sections 3.2-3.7 were taken from different countries to illustrate the disease burden caused by brain diseases internationally. It is important to note that there may be some uncertainty associated with the figures, as the definition of brain disease may vary from country to country. Although the figures should therefore be interpreted with some caution, they do provide a picture of the extent of these diseases.

A study among the Danish population showed that the incidence of brain diseases was just over 33% in 2015 and that it had increased to just over 35% by 2021 (Fuglsang, 2025). Over the past 30 years, brain diseases have increased globally by 64% (from just over 2.5 billion in 1990). This trend is expected to continue unless effective measures are implemented (IHME Brain Health Atlas, undated).

It is believed that one in three people in Norway will develop a brain disease during their lifetime (Government, 2023). According to the Global Burden of Disease Study, Norway is expected to register over one million new cases of brain disease each year going forward (Institute for Health Metrics and Evaluation (IHME)(2022).

Extent of patients in contact with the specialist health service

In 2022, almost half a million patients in Norway came into contact with the specialist health service with brain disease as a primary or secondary diagnosis (Directorate of Health, 2024a). This is equivalent to around 9% of the population. The number of patients has been rising steadily in recent years. Mental and behavioural disorders accounted for over 60% of cases, while nervous system disorders accounted for nearly 40%. The incidence of brain diseases was highest in Northern Norway and Southeastern Norway. The largest increase was observed among women under the age of 45, linked to mental and behavioural disorders in particular. Brain diseases represent a significant and increasing burden on the specialist health service, especially in relation to mental disorders.

Morbidity and mortality

Around 9 million people die every year from brain diseases, according to the World Health Organization (Oslo Economics, 2024). According to the Norwegian Government (2023), brain diseases are the second most common cause of mortality in Norway. IHME Brain Health Atlas (undated) forecasts that nearly half a million people in Norway will die from brain diseases in 2050.

A study by Vestergaard et al. (2020) showed that mortality was five times higher in people with a brain disease in Denmark compared with the rest of the population.

Brain diseases are among the leading causes of disease and disability, accounting for 35% of Europe's total disease burden (Di Luca et al., 2018). The period from 2010 to 2017 saw an increase in the disease burden (Raggi & Leonardi, 2020).

Studies show that brain diseases are the most prevalent and burdensome disease group of the non-communicable diseases (NCDs) among the European population aged 15 years or older. The disease burden resulting from brain diseases is increasing due to the transition from acute diseases to chronic diseases, increased life expectancy and many socioeconomic, environmental and behavioural health factors (Di Luca et al., 2018).

Functional impairment and disability

Brain disorders can affect brain function and give rise to varying degrees of impairment, including in relation to cognitive and emotional function, mobility and communication. Living with a brain disease can significantly affect quality of life and is also associated with major consequences such as distress, stigma, social isolation and discrimination (Boon et al., 2025). Brain diseases are the most frequent cause of disability among the Norwegian population (Government, 2023).

Diseases of the brain account for just over a third of the years that people in Norway live with disability (Nilsen, 2018). People with brain disease are more likely to take sick leave and be unemployed. More people retire earlier and have a significantly lower life expectancy than the general population (German Brain Council, 2022).

In 2023, almost 22,000 people aged 18-29 years were in receipt of disability benefit. Nearly 70% of these individuals had diagnoses within mental and behavioural disorders, while just over 11% had neurological diseases. Just over 11% had congenital malformations and chromosome abnormalities (NAV, 2025).

Economic burden caused by brain diseases

Estimates by the IHME Brain Health Atlas (undated) indicate that USD 1.1 billion was spent globally treating brain diseases in 2019. The global cost of brain diseases rose by just over 5% annually during the period 2000-2019. During the same period, the annual average growth rate in the global population was around 1.10-1.30% (United Nations, 2022).

In 2010 and 2012, neurological and mental disorders in Europe led to annual costs of approximately EUR 800 billion (Boon et al., 2023; Gustavsson et al., 2011; Olesen et al., 2011). Medical costs, including medications and hospital costs, accounted for 37% of the expenditure, while 23% was spent on non-medical costs, such as nursing and care. A total of 40% consisted of indirect costs as a result of loss of work capacity, for example.

In Germany, brain diseases entail costs of more than EUR 60 billion annually for the health system. This corresponds to almost 20% of all national spending on health (German Brain Council, 2022).

A cohort study by Fuglsang et al. (2025) found that the total direct costs associated with individuals with brain diseases amounted to EUR 7.5 billion in both 2015 and 2021, while the total indirect costs rose from EUR 17.7 billion in 2015 to EUR 23.2 billion in 2021. Brain diseases are probably the greatest economic burden for the European healthcare system, both now and in the future (Gustavsson et al., 2011; Olesen et al., 2011).

In Norway, brain diseases account for six of the ten diagnoses associated with the highest health costs (Kinge et al., 2023). Collectively, mental and drug-related disorders and neurological diseases are the two largest expense items. Mental and drug-related disorders accounted for almost 21% of Norwegian health expenditure in 2019, with costs of NOK 65 billion. In the 15-49 age group, almost half of all health expenses were linked to mental disorders and drug use. Neurological diseases accounted for just over 15% of health expenses, with costs of over NOK 48 billion. Neurological diseases represent the largest spending category among people over the age of 70 (Kinge et. al, 2023).

In 2010, the cost of brain diseases in Norway was approximately NOK 100 billion per year (Norwegian Brain Council, 2021, p.15). However, it is believed that current costs as a result of brain diseases are even higher, based on recent international calculations. According to a study by Kinge et al. (2025) on health expenditure in Norway from 2022 to 2050, costs attributable to neurological disorders are expected to rise by more than any other health expenditure. Expenses for mental disorders and substance abuse disorders are also expected to rise.

Common needs and challenges within the field of brain health

Brain health encompasses a broad field: the preservation and enhancement of brain health and function, the prevention of injury and disease, as well as what is to some extent a very wide range of diseases, injuries and conditions. However, some needs and challenges are applicable across the board and form the basis for joint efforts in the field. This is, for example, apparent both from the knowledge base and political documents and through the insight work relating to the brain health strategy.

Those affected by brain diseases can face different challenges to varying degrees at different stages of the development of the disease. Some people with brain diseases face complex and extensive challenges that greatly affect them in their everyday lives, while others face challenges which, although they may appear less apparent to others, can collectively be very burdensome to them, their relatives and society as a whole.

The list of challenges and needs may be extensive, but the Directorate of Health has opted to highlight some of the most prominent and key challenges that can affect several groups of brain diseases.

Stigma, invisible symptoms and diagnostic overshadowing

Many people encounter prejudice due to their brain disease and many do not disclose their condition to others out of fear of being stigmatised (Lang et al., 2022). In a survey of individuals with neurological conditions, 84% stated that they experience stigma as a direct result of their condition (European Federation of Neurological Associations (EFNA), 2024). The three main areas in which stigma is most often experienced are in interaction with health professionals (46%), in the workplace (19%) and in the community (11%) (ibid.).

A number of causes may lie behind this stigmatisation, including a lack of understanding (European Federation of Neurological Associations, 2018). Stigmatisation can cause people who experience symptoms or are affected by brain disease to decide not to seek help and treatment. It can also lead to mental health problems, functional impairment and poorer quality of life. Many people also encounter discrimination due to brain disease (Simonsen et al., 2019). In some cases, brain disease can reduce insight into one's own functional impairment and thereby impair the person's ability and motivation to seek help and follow-up treatment themselves (Landi et al., 2016).

Some people experience diagnostic overshadowing, where it can be challenging to find the right diagnosis because it is overshadowed by another diagnosis (Elgen & Lyngre, 2021).

One survey found that 56% of respondents had difficulty describing their symptoms to their doctor, which in part led to 67% being misdiagnosed (European Federation of Neurological Associations (EFNA) (2024).

For many individuals with a brain disease, their symptoms can be almost invisible (European Federation of Neurological Associations, 2018), while the disease burden as a result of the health challenges they have to live with is considerable. In its survey, the European Federation of Neurological Associations (EFNA) (2024) reported that respondents stated that three of the most widespread invisible challenges they encountered were fatigue (85%), pain (74%) and sleep problems (74%).

Treatment and follow-up

Effective treatments are available for some brain diseases, while for others there is no curative treatment. This means that individuals with a brain disease often have to live with chronic problems for a long time. The focus will therefore be placed on symptom relief, prevention of deterioration and maintenance of function. The conditions vary in cause, symptoms and course, but they can all significantly affect quality of life and require long-term treatment and follow-up (Steinmetz et al., 2024).

For those living with a chronic disease, good support is important in enabling them to maintain a healthy lifestyle and level of functioning and to master their own health and life situation. Many people living with a brain disease do not receive adequate follow-up for a number of reasons. Individuals with multiple chronic diseases have varied needs that are often not met by ordinary treatments (Meld. St. 9 (2023-2024)). The complexity of the conditions can make it difficult to make accurate diagnoses and provide proper treatment. This can lead to misdiagnosis and delayed

treatment, which in turn can further exacerbate symptoms and increase the burden on patients and caregivers (Ningrum & Kung, 2023).

Knowledge and health literacy

Surveys indicate that people know less about brain health than other health challenges (Budin-Ljøsne et al., 2022; Fredheim et al., 2021). Better knowledge among the population could help individuals to improve their own brain health. A significant proportion of the population also has a low level of health literacy generally (Le et al., 2019), which limits the ability of the population to be active participants in their own health and overcome health challenges. For many brain diseases, we know a lot about effective preventive measures, which are in line with the prevention of other cardiovascular diseases (Aamodt et al., 2024). However, brain diseases cover a wide range of different diseases and conditions and only limited knowledge is available concerning some of them as regards what is needed to prevent them (Wang et al., 2020).

A systematic review of the population's awareness of brain health shows that, although many people do have a knowledge of brain health, fewer people actually take action in a way that is good for their brain (Niechcial et al., 2025). This indicates a need to motivate the population into changing their behaviour in order to promote their brain health. Views also varied according to age, gender and socioeconomic status. It is therefore important to include under-represented groups in order to obtain a better knowledge base and adapt the information to their needs (ibid.).

User involvement

The right to self-determination is one of the most fundamental human rights. It is essential for achieving many other human rights and important for safeguarding human dignity (Skarstad, 2019). In accordance with the Patient and User Rights Act, users have the right to be involved and have a say in their own treatment by the health service and the health and care services are also obliged to involve users.

A survey conducted by Olsson et al. (2025) on barriers to user participation in municipal healthcare identified two key findings. The study revealed that participants did not believe that there was a holistic plan for user participation, which had an adverse impact on the level of user participation. The second finding was that it was more difficult to enable users to actively take part in the health services, because the organisation did not have a culture that supported user participation (ibid.).

User participation at group and system level assumes that the experiences of patients and relatives are actively utilised to improve and further develop healthcare services. However, significant differences remain as regards how municipal health and care services and the specialist health service emphasise and safeguard user participation (Ministry of Health and Care Services, 2017). There are also challenges in ensuring user participation in research (Bjåstad et al., 2024).

The role and challenges of relatives

Relatives play a crucial role and their contributions are considered to be just as comprehensive as those of professional care (Ministry of Health and Care Services, 2020). Most patients and relatives want to play a more pivotal role in monitoring their own condition. Self-care training throughout the course of a condition is essential in meeting this need (Ministry of Health and Care Services, 2017).

Being a caregiver to someone with a brain disease can be demanding. The persistent worry and high stress levels that often arise when a loved one has a brain disease can lead to a number of health challenges for relatives. Factors such as the role of the person affected, concerns about the future, the care tasks themselves, how the person deals with their own brain disease and support from relief agencies can all influence how individual relatives perceive the burden (Pårørendesenteretr, 2017).

Children are affected when a parent or sibling develops a brain disease. Being a caregiver as a child can mean less time spent with parents because of illness and treatment and more time alone. Routines can change and everyday life can become more unpredictable. Parents may also have less energy to be emotionally present for their children because they are affected by the situation and have obligations that need to be fulfilled (Bergem, 2022). Children who are relatives may experience mixed emotions when their own needs are disregarded. They may feel guilt, anger, disappointment and shame and be afraid that they will also develop the brain disease that their parents or siblings have. They may also experience a lack of information and recognition (Ytterhus, 2024).

It will be important to take account of the family perspective, so that services for individuals with brain disease and their relatives become more involved and safeguarded (Akershus University Hospital Trust, 2015).

Organisation and cooperation within the health and care services

In order to provide high-quality care and treatment, close cooperation between the various levels of the health and care services is essential. Many people with brain disease need extensive help from both the municipal health and care services and the specialist health services. Many find that the health and care services are not sufficiently well coordinated and have to organise their own healthcare (Meld. St. 9 (2023-2024)). One particular challenge in this context is the management of comorbidity between mental disorders, neurological disorders and/or dependency disorders. For some people with brain disease, it can be difficult to determine what is the right health service for assessment and treatment (Oslo University Hospital, 2021). It can also make it harder to develop suitable strategies for promoting and safeguarding brain health (Bèque et al., 2025).

The way in which health and care services are organised can have consequences for brain health among the population (NOU 2016:17, 2016), for example by leading to unwanted variation (National Audit Office, 2019-2020). The Government's goal of more preventive health and care services can lead to long-term health benefits, including within brain health. This can lead to better resource utilisation and reduce the pressure and financial strain on the health and care services (NOU 2023:4, 2023).

Rehabilitation services

The rising number of elderly people with concurrent conditions and long-term treatment needs is creating additional needs as regards the better coordination of services (Meld. St. 9 (2023-2024)). Studies show that many patients with brain disease do not receive the rehabilitation services they need from the municipal health and care services or the specialist health service. Furthermore, it appears that the cooperation between the municipal health and care services and the specialist health service is not meeting the needs of patients. The availability of specialised rehabilitation

services varies between health authorities (National Audit Office, 2024a). Helseatlas (undated) shows that the use of health services in connection with many chronic brain diseases varies depending on where the patient lives.

The National Audit Office (2024c) notes that the inadequacy of rehabilitation services can have serious consequences for the health of people with brain disease and their ability to work, lead a fulfilling family life and pursue leisure activities. In 2023-2024, the National Audit Office (2024c) carried out a study of rehabilitation services in the health and care services in Norway. The survey found that many municipal health and care services lacked statutory rehabilitation expertise. The survey also indicated that the management of rehabilitation services is inadequate at every level (ibid.).

Agenda Kaupang (2024) has conducted a survey among 27 Norwegian municipalities concerning variations between municipalities that should be taken into account in the work to strengthen the rehabilitation field. The survey identified challenges relating to demographic trends, municipal finances and personnel shortages. It was also found that few municipalities have established structures or arenas for working with rehabilitation at system level, even though rehabilitation has been the focus of more attention in recent years. The organisation of rehabilitation services varies, with larger municipalities often using a centralised model with a higher degree of specialisation, while smaller municipalities tend to have a more decentralised organisation (ibid.).

Agenda Kaupang (2024) also showed that one general challenge is a lack of access to relevant management data, both nationally and locally. A number of municipalities point out that current systems such as IPLOS are unsuitable for rehabilitation purposes and call for national quality indicators. Furthermore, there are challenges in the interaction with the specialist health service, including task-shift and lack of equivalence (ibid.).

Habilitation services

Many people with habilitation needs face major health challenges and therefore need extensive health and care services. Many people also need services from various stakeholders in order to lead a good life with good brain health (Directorate of Health, 2024b). Families with children who face complex challenges often need support from several services (Tøssebro et al., 2023).

However, studies also show that there are substantial differences and insufficient capacity among the health trusts' habilitation services as regards children and young people (National Audit Office, 2021). There are considerable variations between municipalities as regards the use of relief. The way in which the various offices of the county governors handle appeals against individual decisions regarding the health and care services among the municipalities is of great importance in determining which services children and their families receive. Limited information is available regarding how families can get help, which means that the families of children with habilitation needs often have to obtain information and seek help themselves. Coordinating the services around children with habilitation needs works to a limited degree. As a result, many families find they need to coordinate the services themselves (ibid.).

Individuals with habilitation needs have a higher incidence of comorbidity compared with the rest of the population (McCarron et al., 2011). Many individuals have several chronic conditions (Hermans & Evenhuis, 2014) and are at greater risk of developing additional challenges, such as sensory impairments, central nervous system disorders and sleep problems (Oeseburg et al., 2011). They are among the most frail (Ahlström, 2020) and are at greater risk of dying (Reppermund et al., 2019). Although individuals with habilitation needs often encounter health challenges more often

than the rest of the population, they rarely get the help they need for these challenges (Bitsko et al., 2009).

Many people with habilitation needs understand what a healthy lifestyle means, yet it still seems difficult for them to make healthy choices (Kuijken et al. 2015). This indicates that individually tailored measures will be needed to design, implement and follow up on health-promoting measures for this group. Among other things, consideration should be given to the individual's lifestyle and health needs, in addition to preferences, motivation for changing behaviour, physical disabilities, cognitive functioning and the need for guidance and assistance from others (ibid.).

Polypharmacy

For individuals facing chronic health challenges, as in the case of many people with brain disease, it is often the caste that several regularly take five or more medications at the same time (Varghese et al., 2024). This is known as 'polypharmacy' and is common in both the elderly and younger people in risk groups. Polypharmacy increases the risk of negative consequences such as falls, frailty, disability and mortality (ibid.).

According to Strand et al. (2023), 67% of people living at home over 65 years of age took five or more drugs in 2016, while 28% took ten or more. The Norwegian Prescription Database does not include people living in nursing homes. Polypharmacy and the risk of side effects would probably be higher if nursing home residents were to be included (ibid.).

According to the World Health Organization (2019), polypharmacy is a major and growing public health problem among all healthcare services worldwide.

Research and socioeconomic burden

Norway has a long history and solid background in research on the brain and research has made significant contributions to many clinical research fields. However, there are still brain diseases where not enough is known about the causes and treatment methods are ineffective (Kumar et al., 2024). The increasing incidence of brain diseases is placing considerable strain both on those affected and on the socioeconomy (Storstein, 2020; Wang et al., 2020; Zhang et al., 2020). More research is needed to learn more about brain health, understand the mechanisms behind brain function and dysfunction and find effective methods for promoting brain health and treating brain diseases (Wang et al., 2020).

Survey of the National Brain Health Strategy (2018-2024)

Summary of findings

The Directorate of Health wanted an objective evaluation of the previous brain health strategy and therefore commissioned Oslo Economics to conduct an external survey in 2024. The results are included in the knowledge base for the updated strategy. The survey, which is based on the four main objectives of the previous strategy, included a document review, the collation of statistics, interviews with almost 40 informants and a workshop. The project group, partnership and working group contributed views ahead of the final design stage. Key findings from the survey and assessments by Oslo Economics are summarised below. See Appendix 4 for a full review of the report on the survey.

5.1.1 Evaluation of objective 1 – Good lifelong brain health, prevention and quality of life

The Directorate of Health has implemented information measures and campaigns with a broader focus than brain health, including physical activity and diet. It is uncertain whether the brain health strategy has played a pivotal role in these. A thematic page about the brain, brain health and brain diseases has been added to helsenorge.no, in addition to a page on the Directorate of Health's website. It is unclear whether the strategy has led to more quality-assured healthy living, learning and coping services. The survey suggests that the strategy has not boosted health promotion and preventive initiatives among the health and care services. Although there have been some positive developments, the findings show that there is room for improvement, particularly in terms of preventive measures and quality of life.

5.1.2 Evaluation of objective 2 – A more user-centred healthcare service and better care for relatives

Two decision aids for brain diseases have been developed and others are considered to be beneficial. User organisations have contributed to thematic pages on brain health on helsenorge.no. NeuroNet was inspired by ParkinsonNet, but is not directly related to the strategy. EpilepsyNet (epilepsinett.org) was established as part of the brain health strategy. Respondents believe there is a need for more multidisciplinary networks. The brain health strategy has had limited impact on measures and activities. The work on the relatives strategy is not directly linked to the brain health strategy. Progress has been made towards a more user-centred offering, but further improvements are still needed, especially as regards accountability and objective follow-up.

5.1.3 Evaluation of objective 3 – Good care from the onset of symptoms to diagnosis and treatment, to habilitation and rehabilitation

The survey showed that there have been no major changes in ensuring coordinated and multidisciplinary services. There is considerable variation in the offerings, especially at the transition from child to adult. Municipal rehabilitation services are inadequate and there is uncertainty as regards whether local or centralised services are better for patients. National treatment lines have been developed for children with acquired brain damage. Not everyone with brain diseases sees their right to an individual plan and coordinator fulfilled. The Directorate of Health is working on measures relating to dementia, including national professional guidelines.

Learning networks for health professionals have seen broad participation from among the municipalities. The findings reveal both challenges and advances in the work relating to appropriate care pathways for individuals with brain disease.

5.1.4 Evaluation of objective 4 – Adequate knowledge and quality through research and innovation

The Research Council of Norway's funding has strengthened research into brain health and brain diseases. User involvement has taken place irrespective of the strategy, but initiatives such as Neuro-SysMed and EpilepsyNet are results of the strategy. The NorTrials centres, including one for brain health, are promoting new solutions through public-private sector collaboration. New quality indicators have been introduced, but more are needed, especially in the field of mental health services and the multidisciplinary specialised treatment of substance abuse disorders. The national management system for health and social education was established before the strategy. E-learning programmes have been developed, but systematic sharing of training and experiences is lacking. This shows both progress and a need for improvement as regards our knowledge of brain health.

Recommendations from Oslo Economics following the survey

The key points in Oslo Economics' recommendations regarding the updated brain health strategy are as follows:

- Target group and format: The strategy must clarify the target group and delegation of responsibility, as well as having clear funding.
- **Specific to brain health:** The strategy should focus to a greater degree on brain health and complement other relevant strategies.
- Assessment of objective attainment: Use specific targets or indicators to assess objective attainment, which will make the strategy more binding.
- **Timeline:** A clear timeline for the goals might be a positive development, as either the strategy period or separate timelines for different objectives.
- Follow-up of the objectives: Consider how objectives should be followed up, including baseline measurement as and when necessary.
- Aids: Consider what aids should be used, such as knowledge, funding and organisation.

Summary of input

This chapter presents a summary of written input submitted to the Directorate of Health prior to preparation of the background report and the draft updated brain health strategy. By way of introduction, a summary of input from the consultation conference held on 6 June 2024 is presented. The key aspects of the input submitted to the Directorate of Health in the consultation

round during the period 6 June -20 June 2024 are then presented. Finally, the key points from the input from members of the Norwegian Brain Council are presented. The summaries do not cover all the input that was submitted, but instead provide an overview of the key topics and views.

Consultation conference: Summary of input

For a more detailed understanding, see Appendices 5, 6, 7 and 8, where all input is transcribed.

6.1.1 Input concerning objective 1 – Good lifelong brain health, prevention and quality of life

- The life course perspective: It is important to take account of the entire life course, in addition to primary, secondary and tertiary prevention. This involves measures for both individuals without brain disease and those who already have it.
- **Prevention:** A stronger focus is needed on preventive measures, such as reducing substance abuse, improving brain health literacy through campaigns and promoting universal measures such as sleep and physical activity.
- **Social inequalities:** Addressing social inequality, childhood, health literacy and greater expertise among the health and care services are key areas.
- Improve brain health literacy among the population: There is a need to improve brain health literacy both among the general population and among individuals with brain disease.
- **Brain health in education:** Brain health should be covered in multidisciplinary professional courses for health and care professions.
- Universal or specific measures: There were differing opinions as regards whether it is more
 important to have universal measures aimed at everyone, or just certain specific measures
 aimed at vulnerable/exposed groups.

6.1.2 Input concerning objective 2 – A more user-centred health and care service and better care for relatives

- User involvement: It is important to listen to users at both micro and macro levels.
 Cooperation with voluntary user and relative organisations will be important in order to obtain user expertise.
- Services aimed at relatives: It is essential to think holistically and include the whole family. Information that relatives need should be provided and children who are relatives must be given priority and receive age-appropriate information.
- **Training for relatives:** Relatives often act as coordinators and should be helped to perform this role. It is also important to safeguard the family's own health.
- Brain health coordinator: It was suggested that the role of brain health coordinator be created among the municipalities to improve expertise and coordinate services for patients and relatives.
- **Decision aids:** There were proposals to develop and introduce a number of decision aids for patients with brain disease, so that patients can actively take part in decisions concerning assessment, treatment and follow-up.

6.1.3 Input concerning objective 3 – Good care from the onset of symptoms to diagnosis, treatment, habilitation and rehabilitation

- Multidisciplinary collaboration and coordinated services: It is important to create
 multidisciplinary and coordinated services that take into account the needs and wishes of the
 patient. This can lead to better treatment and care of patients and relatives.
- **Primary objectives and sub-objectives:** The sub-objectives need to be tidied up. For example, there is no overarching plan regarding who will treat different sleep problems.
- The transition between the primary and specialist health services: There are challenges as regards the transition between the primary and specialist health services and it is therefore important to clarify what should be at the various levels.
- Treatment and resource networks: It will be essential to ensure appropriate treatment, particularly for unresolved conditions. Resource networks can contribute to equitable treatment, but they do require dedicated resources.
- Care: There is a need for structured and seamless care

6.1.4 Input concerning objective 4 – Adequate knowledge and quality through research and innovation

- Research and innovation: More research and innovation are needed to develop the health and care services, especially during critical periods such as the early years of children's lives.
- **Collaboration:** It is important to establish national research centres and promote cooperation, both nationally and internationally.
- Rare brain diseases: Research concerning rare brain diseases and the implementation of research-based knowledge are necessary.
- **Education:** There is a need to educate more people in specialised fields in which there are major shortcomings, such as speech therapy and audiology.
- **Technology:** There is a desire to develop artificial intelligence tools that can help with diagnostics and follow-up.
- Quality registries: There is a need to establish standardised national quality registries for the further development of services.

The consultation round: Summary of input

See Appendix 9 for details of the input.

Multidisciplinary approach and concurrent ailments:

- There is a need for a holistic approach that takes account of concurrent ailments and symptoms. This may include multidisciplinary cooperation between disciplines.
- Consideration should be given to diagnostic-specific treatment options, as some diagnoses have overlapping symptoms and may benefit from existing treatment methods.

Individual facilitation and follow-up:

- School and working life should be better facilitated for individuals with brain diseases. This
 may include adaptations, individual follow-up and support.
- Lifelong rehabilitation and follow-up are essential, especially for patients with primary brain tumours. This should take place in close cooperation between the specialist health service and the municipalities.

Research and knowledge:

- There is a gap between research and practical application. More research is needed concerning neurodevelopmental disorders and simultaneity.
- A knowledge of brain health and diseases should be made an integral part of relevant courses and professions.

User participation and support for relatives:

- Patient and user organisations play an important role in the development and evaluation of services.
- Relatives, including children as relatives, need better support and follow-up.

Sleep disorders as a public health challenge:

Sleep disorders should be taken seriously. Specialised sleep clinics and trained personnel
can contribute to proper diagnosis and treatment

Summary of input from the Norwegian Brain Council

The Norwegian Brain Council proposes a number of specific sub-objectives and initiatives for the updated brain health strategy. They expect the strategy to meet needs that other documents do not and want to see a holistic approach to brain diseases adopted. The sub-objectives from 2018-2024 should be revised to address specific challenges. They emphasise the need for clear definitions of 'brain disease' and 'brain health', clear responsibility, as well as follow-up throughout the strategy period. They recommend that the organisation in the form of a partnership be continued. Key aspects of the input from members of the Norwegian Brain Council are presented below. See Appendix 10 for more details.

6.3.1 Input concerning objective 1 – Good lifelong brain health, prevention and quality of life

The Norwegian Brain Council believes that the updated brain health strategy should strengthen health-promoting and disease-prevention measures, with a focus on primary and secondary prevention. Measures must be implemented to prevent brain disease in the population, prevent disease burden and facilitate better quality of life for those affected by brain disease and their relatives. The strategy should emphasise health literacy, information measures and social responsibility. In addition, challenges such as the lack of expertise within the field and the need for multidisciplinary initiatives should be addressed. Norway should become a pioneer in the

prevention of brain disease. The sub-objectives under primary objective 1 should include expertise within the field in education, research, knowledge availability, as well as good brain health in pregnancy, childbirth and maternity care.

6.3.2 Input concerning objective 2 – A more user-centred health and care service and better care for relatives

The Norwegian Brain Council believes that the previous brain health strategy contains unclear boundaries between primary objectives 2 and 3. Relatives play a critical role in strengthening the decision-making skills of patients with brain disease. There is a need for more binding cooperation between public and voluntary sector stakeholders in the health sector and the Norwegian Brain Council recommends that new sub-objectives be introduced to promote this, including an annual grant scheme. The proposals for sub-objectives under primary objective 2 include pilot models for collaboration with the voluntary sector, a coordinator role, decision aids and rights in connection with the burden of care among relatives.

6.3.3 Input concerning objective 3 – Good care from the onset of symptoms to diagnosis, treatment, habilitation and rehabilitation

The Norwegian Brain Council proposes improvements within diagnostics and rehabilitation, as well as enhanced interaction across service levels and life phases. The strategy's sub-objectives should be revised to improve the quality of care pathways. Municipalities should develop follow-up programmes for the chronically ill and support collaborative projects with the voluntary sector. Equitable access to personalised medicine and systematic assistance is needed for the chronically ill and their relatives. The expertise of health professionals must be strengthened in order to facilitate the more effective management of brain disease. The Norwegian Brain Council proposes sub-objectives concerning the expansion of ParkinsonNet, structured care pathways, a trans-regional treatment network, multidisciplinary specialised rehabilitation and the mapping of diagnostic delay.

6.3.4 Input concerning objective 4 – Adequate knowledge and quality through research and innovation

The Norwegian Brain Council believes that improving the treatment and follow-up of patients with brain disease will require an increase in research funding. Research results must be implemented effectively and advanced treatments should be made available in Norway. There is a need for a better overview of research areas that need strengthening, especially as regards living with the disease. The brain health strategy should include quality registries and increase knowledge concerning patient experiences. Clinical research must be given a higher priority and be better integrated into hospital operations. Some of the proposed sub-objectives include the establishment of new research centres, the continuation of NeuroSysMed and NorHead, more quality and treatment registries and a knowledge base for the disease burden linked to brain diseases.

International knowledge and experience concerning brain health

The Directorate of Health believes that international exchange of experience concerning brain health would provide an opportunity to learn from other countries and share knowledge, which in turn can promote brain health in Norway. In addition, international collaboration can be important for promoting better brain health globally. The Directorate of Health has therefore reviewed strategies, programmes and plans for brain health from other countries and held meetings with relevant professionals and organisations. This chapter gives a concise account of the key aspects of international strategies, plans and programmes for brain health. To understand the content of the various international brain health plans, it is recommended that they be read directly, as translations may be imprecise.

7.1 World Health Organization

In 2022, the WHO launched a global strategy for brain health. This strategy describes what brain health entails, identifies factors that help promote brain health throughout a life course and identifies the basis for good brain health. During the development of this strategy, the Directorate of Health was in regular contact with the WHO. As a result of the WHO's initiative, Norway's experiences of coordinating the country's brain health strategy are referred to in the WHO's global brain health strategy (on page 69, box 9) (World Health Organization, 2022).

The WHO describes five factors, or areas, that affect brain health throughout a life course. These areas apply at both individual and system level. The factors are: (1) physical health, (2) health-promoting environment and climate, (3) safety and security, (4) learning and social connection and (5) equitable access to high-quality services. The five areas have many underlying goals that can help optimise brain health throughout a life course. The goals under the five areas primarily target the health and care sector, education, legislation, finance and economics, work and infrastructure (ibid.).

7.2 European Academy of Neurology

The European Academy of Neurology (<u>EAN (ean.org)</u>) is an association for national neurology associations in Europe. The association has developed a brain health strategy called "One brain, one life, one approach", which was launched in 2022. The strategy was created by researchers and specialists from institutions and organisations across Europe (Bassetti et al., 2022).

The EAN's brain health strategy contains five key points: (1) collaboration concerning brain health to promote brain health globally, (2) support for European neurological communities and health policymakers in initiating campaigns aimed at individuals and their needs. They (3) also encourage research into how brain diseases can be prevented and brain health safeguarded and (4) work to increase knowledge of brain health among students, neurologists, general practitioners, health professionals, patients, caregivers and the rest of the population. They also want (5) to raise awareness among the general population of brain diseases and the importance of good brain health (ibid.).

7.3 Sweden

The Swedish Brain Foundation (2022; 2023a) has developed a plan called "A plan for the brain". The aim of this brain plan is to urge the Swedish Government to draw up a national strategy and action plan for the brain.

The Swedish Brain Foundation proposes six target areas:

- 1. **Well-being throughout life:** Promote the well-being and health of citizens as an investment, with continuous preventive measures.
- 2. Learning environment: Provide all children and adolescents with the prerequisites necessary to achieve goals at kindergarten and school, with inclusive and safe learning environments and competent staff.
- **3. Safeguarding and care of the brain:** Organise health and care services with the right skills and continuous follow-up, reduce the number of stroke cases and suicide through prevention and treatment.
- **4. Better support for relatives:** Ensure the safety of and support for relatives of individuals with brain disease, injuries and functional impairments.
- **5.** Research, development and innovations for the brain: Increase government funding for brain research and strengthen multidisciplinary collaboration.
- **6. Brain-friendly education and societal development:** Promote well-being and development, reduce negative factors for the brain and prevent brain diseases and injuries

7.4 Finland

The Finnish National Brain Health Programme (Aivoliitto, 2022a) was launched by the Finnish Brain Association (Aivoliitto) in 2022. The programme period will last at least seven years, from 2023 to 2029. The Finnish Brain Association and partners are responsible for implementing the programme. The programme is aimed at three age groups, with common objectives adapted to each group. It emphasises result-oriented thinking and a proactive approach, focusing on protective factors. The long-term aim is to create a sustainable society that supports brain health, with the following performance goals to achieve this:

- Understanding brain health and brain diseases and valuing brain well-being have been strengthened
- Brain ergonomics has been applied to workplaces
- Everyone has an opportunity to have refreshing and restorative sleep
- The sense of belonging has been strengthened everyone is a citizen, together.

In addition to these four performance goals, there is a particular focus on adequate physical activity, healthy nutrition and abstinence from drugs, all of which are fundamental to good brain health. Practical implementation began in 2023 with communication and training and in 2024 the theme is sleep (national brainwashing – with sleep). Finland has also produced an English translation and a Swedish summary (Aivoliitto, 2022b).

7.5 Germany

In 2022, the German Brain Council (2022) launched the German brain plan. The plan period lasts until 2030. The German Brain Council has produced a roadmap, a timeline with focus areas:

 2022/2023: Raise public awareness of the German Brain Plan, networking and identify deficiencies in care.

- 2024/2025: Pilot projects concerning traumatic brain injury and depression, promoting early diagnosis and treatment and rehabilitation
- 2026/2027: Implementation of research findings in clinical practice and improvement of treatment for all brain diseases
- 2028/2029: Assessment of new areas to focus on in further work (ibid.)

7.6 Scotland

Alzheimer Scotland launched a strategy for brain health and dementia research in 2021. This work was carried out in collaboration with various academic and research communities (Alzheimer Scotland, 2021). The strategy will serve as a framework for organisations to create their own action plans to ensure the safeguarding of brain health and research concerning dementia, both locally and nationally. To facilitate this, the strategy recommends four approaches (Alzheimer Scotland, 2021) as follows:

- the creation of local research boards for brain health and dementia
- the establishment of a national forum
- a national survey to identify bottlenecks and barriers that hinder research into brain health and dementia at every level
- the establishment of a national board to oversee the implementation of the strategy across Scotland

7.7 Switzerland

The Swiss Brain Health Plan (Bassetti et al., 2023) has a duration of ten years, from 2023 to 2033. The plan was drawn up by clinicians and researchers with a range of professional backgrounds within the health sector.

The Swiss Brain Health Plan has five goals:

- 1. **Raise awareness** of brain health and brain diseases among the general population and health professionals and increase the political focus on the topic.
- 2. **Strengthen education and training** of health professionals in brain health and brain diseases.
- 3. **Promote research** into brain health, as well as prevention and treatment of brain diseases.
- 4. **Prioritise a holistic approach** to brain health with measures at individual, community and global level and promote collaboration between different groups.
- 5. **Support and involve patients and relatives**, increase user participation, reduce stigma and assess societal and economic benefits

7.8 Poland

The Brain Plan for Poland was developed by specialists in law, economics, neurology and psychiatry, as well as patient organisations. The group that led the work was established by the Neuropozytywni Foundation, the Institute of Healthcare Management at Lazarski University and the law firm DZP. The brain plan was launched in 2019. There is also a summary of the Brain Plan for Poland, which has been translated into English (NeuroPozytywni, undated).

The brain plan includes an analysis of the key systemic challenges within prevention and treatment, as well as direct and indirect costs of five brain diseases (MS, depression, Parkinson's disease,

schizophrenia and stroke). The brain plan has four primary objectives and a number of sub-objectives. In summary, the four primary objectives are as follows:

- 1. Introduce the definition of brain diseases and include the prevention of brain diseases in the directory of health priorities.
- 2. Prevent, diagnose and treat brain diseases through national programmes and the training of doctors.
- 3. Increase investments in brain research and development through the state medical research agency.
- 4. Improve the quality of life of patients and their families through coordinated services.

The Brain Plan for Poland has not been adopted at Ministry of Health level through a government document and brain health has not yet been recognised as a priority within health policy in Poland (Izabella Dessoulavy-Gadysz, personal communication, 28.10.24).

7.9 Italy

The Italian Brain Health Strategy was developed by the neurological association Società Italiana di Neurologia (2024a), abbreviated as SIN. The strategy was launched in connection with World Brain Week in March 2024 (Società Italiana di Neurologia, 2024b) and is based on their manifesto of " *One Brain, One Health*". The strategy period covers eight years, from 2024 to 2031. The plan was drawn up in order to implement the WHO's global and cross-sector action plan for epilepsy and other neurological disorders (World Health Organization, 2023a). Italy supports the WHO's definition of the term 'brain health' as described in the WHO's global brain health strategy, "Optimizing brain health across the life course" (World Health Organization, 2022).

The goals of the Italian Brain Health Strategy are to:

- 1. **Implement the WHO Global Action Plan** in Italy, including health planning, prevention, research, diagnosis, treatment, rehabilitation and social factors.
- 2. **Promote brain health** for all citizens of all ages to reduce the impact of brain diseases.
- 3. **Initiate a constructive dialogue** with patients, health professionals, partners, politicians and the general population.
- 4. Launch a national brain health programme with the active involvement of all stakeholders.
- 5. **Collate different aspects of brain diseases** to create a holistic understanding, in line with the EU initiative "Healthier Together".
- 6. "One Brain, One Health" is placed high on the agenda to ensure greater awareness and focus on the concept.

The Directorate of Health's general assessments and recommendations

The Directorate of Health has received extensive input from stakeholders among user and interest organisations, the municipal health and care services, the specialist health service and the partnership. Insight has also been obtained through a dialogue with relevant individuals from professional and user environments both inside and outside Norway. The survey report from Oslo Economics and relevant documents are other sources which have been included in this work. The

Directorate of Health has also gained valuable experience through coordination of the brain health strategy.

Based on the insight that has been obtained, the Directorate of Health highlights a number of general recommendations concerning Norway's forthcoming brain health strategy:

8.1 A strategy period of ten years

The duration of the updated brain health strategy should be ten years, i.e. from 2025 to 2035. The sub-objectives proposed in the draft are realistic, but also ambitious. It will take time to achieve significant results as a result of the sub-objectives. Brain health is an area that needs a long-term and holistic health perspective throughout life, both for those affected by brain disease and for the rest of the population.

8.2 A holistic approach to brain health

The updated brain health strategy should have a holistic approach which covers a broad spectrum of brain diseases. A holistic perspective can help address multiple and shared needs and challenges at the same time, thus contributing to positive effects for a wider group of individuals.

8.3 Continue the primary objectives from the previous brain health strategy

The Directorate of Health received little feedback concerning the changes to the four primary objectives as they were set out in the previous brain health strategy. The Directorate of Health considers the objectives to be comprehensive. However, the sub-objectives are crucial to achieving the main objectives and it is here that the focus should be placed in the future.

8.4 Fewer and clearer sub-objectives

The Directorate of Health believes that the updated brain health strategy should include fewer and clearer sub-objectives. At the same time, the sub-objectives should be ambitious and the strategy period sufficiently long to achieve them. It will therefore be necessary to have sub-objectives that allow for different approaches and measures in order to achieve them effectively. Having fewer sub-objectives may help to clarify priorities, expectations and resource use and foster a more concentrated effort towards achieving each sub-objective.

8.5 Action plan after launch of the strategy

In the follow-up to the updated brain health strategy, an action plan should be drawn up as an initial step. The action plan should include specific and operational measures to achieve the sub-objectives. This will require a separate assessment of which measures will be appropriate in order to achieve the sub-objectives.

The action plan should include a schedule for implementation of the measures and attainment of the sub-objectives. The plan should also include an explicit delegation of responsibility for follow-up

of the measures. Criteria for the attainment of objectives, either quantitative or qualitative, should also be presented, along with evaluation methods. For the sub-objectives that are considered to be appropriate, the Directorate of Health recommends that baseline measurements be taken.

It is important that regular adjustments and updating of the action plan be facilitated, so that the plan can be adapted to new challenges and needs as they arise. Such adjustments could, for example, take place in the context of status reporting to the Ministry of Health and Care Services; see section 8.6.

8.6 Regular status reports in the work on the brain health strategy

The Directorate of Health recommends that a concise status update be given regularly to the Ministry of Health and Care Services concerning the work on the updated brain health strategy. Such reports can contribute to continuous improvement by identifying areas that are in need of further development. This will provide an opportunity to evaluate and investigate whether adjustments to measures are needed in order to achieve the sub-objectives. Regular reports also promote transparency and provide the Ministry of Health and Care Services with insight into the progress being made and any challenges that have arisen.

8.7 Midway evaluation of the work on the strategy

A mid-term evaluation of all sub-objectives should be conducted halfway through the strategy period for the updated brain health strategy. This will be important in order to assess progress, identify any challenges and adjust the measures to ensure that the sub-objectives are achieved.

8.8 Specific objectives for brain health

The sub-objectives should address needs that are not already covered by existing management documents and strategies. The Directorate of Health believes that the brain health strategy will achieve greater synergies if it supplements, rather than refers to, other strategies and initiatives. The strategy should also focus more specifically on work of relevance to brain health and to a lesser extent on areas that overlap with other public health efforts.

8.9 Utilising experiences at national and international level

The brain health strategy should be based on the experiences gained during the previous strategy period, from other areas of health and disease and from similar work being carried out in other countries.

8.10 Communication document with a strong educational approach

The updated brain health strategy should have a strong educational approach, with a clear message and direction. Efforts should be made to ensure that the strategy document does not appear too text-heavy.

8.11 Maintain collaboration with the partnership and other relevant stakeholders

It is important to maintain close collaboration with the partnership for the brain health strategy and other relevant stakeholders. This collaboration strengthens the work relating to the brain health strategy by offering an insight into challenges within brain health and exploring possible solutions from different perspectives. It can also facilitate the implementation of measures.

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Appendix

Please note that the appendix have not been translated from Norwegian to English.

- 1. <u>Invitasion til innspillskonferanse om utkast til oppdatert hjernehelsestrategi (PDF)</u>
- 2. Spørsmål til innspillskonferanse (PDF)
- 3. Invitasjon til skriftlige innspill frist 20. juni (PDF)
- 4. Kartlegging av status på hjernehelseområdet (PDF)
- 5. Innspill mål 1 innspillskonferanse den 6. juni 2024 (PDF)
- 6. Innspill mål 2 innspillskonferanse 6. juni 2024 (PDF)
- 7. Innspill mål 3 innspillskonferanse den 6. juni 24 (PDF)
- 8. Innspill mål 4 innspillskonferanse den 6. juni 24 (PDF)

- Samlede innspill til utkast til oppdatert hjernehelsestrategi innspillsrunden (PDF)
 Hjernerådets innspill til oppdatert hjernehelsestrategi (PDF)
 Vedlegg tilbakemelding offentlig høring (.zip)