

A close-up portrait of an elderly indigenous person, likely from the Sami or Inuit region, wearing a thick, grey fur parka with a large fur collar. They have a serious expression and are looking directly at the camera. A colorful braided cord with a tassel hangs from their neck. They are holding a large, round, woven basket made of light-colored straw or reeds. The background is a plain, light blue-grey color.

Indigenous peoples and dementia in the Nordic region



Nordic Welfare
Centre

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Introduction

Collaboration on social policy issues from the perspective of indigenous peoples is a good example of Nordic added value. The communities served by the policies are relatively small and live in countries that, to a large extent, share common challenges such as ageing populations, personnel shortages and large geographic distances.

In the field of dementia, the Nordic countries' collaborations are coordinated by the Nordic Welfare Centre. Said collaborations have demonstrated a need to: establish baseline knowledge; systemise exchanges of findings; and, create an arena for discussing what is good care and welfare for Sámi and Inuit dementia sufferers. As regards said care and welfare, there is a lack of research and evidence-based knowledge. However, certain initiatives and research projects are under way in Finland, Norway, Sweden and Greenland.

This report summarises conclusions and proposals from group work at the first Nordic conference on indigenous peoples and dementia. Jointly organised by the Nordic Welfare Centre, Region Jämtland Härjedalen (Jiemhten Herjedaelien Dajve in South Sámi) and Staare 2018 (an event celebrating a Sámi centenary), the conference was held in Östersund (Staare in South Sámi) in autumn 2018. Amongst other things, this report covers: the concrete measures and changes necessary for indigenous dementia sufferers to receive better support and service in Nordic municipalities; how knowledge can be shared across municipalities and countries; and, how new knowledge can be implemented in practice. Although compiled by the Nordic Welfare Centre, the working groups' views do not express any prioritisations or recommendations on the centre's part.

The Nordic Welfare Centre has been assigned the task of contributing to the development of welfare measures in the Nordic countries. This is to be done by: compiling and spreading knowledge; and, creating arenas for networks and research collaborations. In spring 2019, a new Nordic network was established in the field of indigenous peoples and dementia. It comprises public authority representatives, researchers and care and welfare professionals in Finland, Norway, Sweden and Greenland. This report is intended as input for: discussions on prioritisations in Nordic collaborations centred on indigenous peoples and dementia; and, local and national

debates on measures at municipal and national levels. To provide some background to the proposals, the report begins by sketching out the present state of knowledge in respect of indigenous peoples and dementia in the Nordic region.

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Sketch of the present state of knowledge

Indigenous peoples of the Nordic countries

The Nordic countries have two indigenous peoples. These are the Sámi in Finland, Norway and Sweden and the Inuit in Greenland. The Sámi administrative districts in the Nordic countries comprise four municipalities in Finland¹, 12 in Norway and 25 in Sweden.

Stockholm is one of these latter. There are no official figures on the number of Sámi people living in the Nordic countries. A common estimate is 50,000 – 65,000 in Norway, 20,000 – 40,000 in Sweden and around 8,000 in Finland. Around 2,000 Sámi people live in Russia. In Greenland, the Inuit people make up the majority (around 87 per cent) of the country's population of just over 56,000.

Special requirements are imposed on any municipality that is a Sámi administrative district in Finland, Norway or Sweden. These requirements vary somewhat between the countries. For example, Sámi people may be entitled to preschooling and elderly care entirely, or preponderantly, in Sámi. They may also be entitled to use their language in contacts with the district's municipalities and public authorities.

The Sámi and Inuit are regarded as indigenous peoples of all Nordic countries. However, only Norway and Denmark have signed the UN's International Labour Organisation convention 169, [Indigenous and Tribal Peoples Convention](#). Furthermore, there are significant differences in how the countries accommodate and honour the indigenous peoples' rights in practice. The UN's global goals for sustainable development and the 2030 Agenda for Sustainable Development apply to all Nordic countries. Said goals and agenda highlight indigenous peoples and the disabled as prioritised groups.

¹ The Finnish municipality of Utsjoki buys Sámi-language welfare services from two municipalities in northern Norway.

The histories of Sápmi² and Greenland have similarities and differences with the colonisation of indigenous communities in other parts of the world. Especially as regards the Nordic part of Sápmi, today's social and national welfare systems differ from those covering indigenous peoples in the modern-day USA or Australia.

A common factor in all western countries with indigenous populations is that, over the past 50 – 60 years, many people with autochthonous backgrounds have moved to large towns. There, they may form a totally invisible minority.

Indigenous peoples and dementia

In principle, there is no joint research or knowledge on: the lives of Sámi and Inuit dementia sufferers in the Nordic countries; and, the national incidence of dementia amongst people with autochthonous backgrounds. In Sweden, Umeå University's ongoing (2018 – 2019) [HALDI research project](#) aims to produce a first mapping out of, amongst other things, the incidence of various neurodegenerative disorders in Sámi and non-Sámi people in Swedish Sápmi.

Small studies from, for example, Canada and Australia, indicate that people with autochthonous backgrounds are affected by dementia to a greater extent than are majority populations.³ However, the studies that have been carried out vary as regards both structure and results.⁴ A 2013 Canadian study shows not only a higher incidence amongst people with a background in the country's so-called First Nations, but also that those affected succumb approximately ten

² Sápmi is the north Sámi name for the areas where the Sámi have historically lived. As a whole, these areas have no formal boundaries.

³ Jacklin K. et al.: [The Emergence of Dementia as a Health Concern Among First Nations Populations in Alberta, Canada](#). *Canadian Journal of Public Health* 104 (1). 2013. Mayeda E. et al.: [Inequalities in dementia incidence between six racial and ethnic groups over 14 years](#). *Alzheimer's & Dementia* 12 (3). 2016. Smith K. et al.: High prevalence of dementia and cognitive impairment in Indigenous Australians. *Neurology* 71 (19). 2008.

⁴ Warren, L. A. et al.: Prevalence and incidence of dementia among indigenous populations: a systematic review. *International Psychogeriatrics* 27 (12). 2015.

years earlier than others and that more men than women receive the diagnosis.⁵

At a global level, indigenous populations have worse health than majority populations in the same area.⁶ This also influences the incidence of dementia and access to correct, good-quality care. Factors particularly affecting the health of indigenous populations are also probably behind increased incidence of dementia.

Although more research than before is now being carried out into the health of indigenous populations, there is still a lack of knowledge regarding how best to prevent, treat and provide customised care for autochthonous people who have dementia. Furthermore, traditional indigenous cultures may have different understandings of dementia. Thus, dementia symptoms may not always be perceived as problematic or related to illness. Similarly, majority populations' diagnostic tools, information and structured care and support for those close to the sufferers may require cultural adaptation for minority populations.

With participants from the USA, Brazil, Canada, Australia and New Zealand, an international network, the [International Indigenous Dementia Research Network](#) (IIDRN), has been established for researchers, students and bodies active in the fields of hospital care, indigenous peoples and dementia. This network aims to raise the profiles of bodies working with indigenous peoples and dementia. The researchers in the network meet physically and digitally to discuss research needs, exchange findings and establish collaborations.

Indigenous peoples, dementia and the Nordic welfare societies

In the care and welfare fields, the rights of Sámi and Inuit people are regulated by international conventions and national legislation. This legislation and the organisation of healthcare and social services vary

⁵ Jacklin K. et al.: [The Emergence of Dementia as a Health Concern Among First Nations Populations in Alberta, Canada](#). *Canadian Journal of Public Health* 104 (1). 2013.

⁶ Anderson, Ian et al.: Indigenous and tribal peoples' health (The Lancet-Lowitja Institute Global Collaboration). A population study. *The Lancet* 388. 2016.

between different countries and municipalities. There are major linguistic and cultural variations between Sámi people in various parts of the Nordic countries and there are Inuit in, for example, small communities in Greenland and the city of Copenhagen (Denmark).

There is no overall picture of how indigenous peoples in the Nordic countries perceive or use welfare services. However, there is some knowledge at the national level. Despite positive developments in a number of areas, there are still barriers to good-quality, person-centred care. These barriers can have major consequences for vulnerable groups. In all Nordic countries, the tripartite division into primary care, specialist care and social services can make coordinated measures difficult. Failure to meet recruitment and skills challenges can result in poor continuity for care and welfare recipients.

In **Norway**, the policy goal has been to culturally adapt established services rather than to develop specific services for the Sámi population. Said population uses healthcare to the same extent as the majority population but is less satisfied with the care that is provided. As regards health status and the prevalence of disease, there do not seem to be any differences between indigenous and majority populations here. Certain researchers focus on the Sámi understanding of health, illness and treatment differing from that of the majority population. There is also literature pointing out that Sámi speak about illness and health indirectly via the use of metaphors. However, the idea that Sámi-speaking people prefer to meet Sámi personnel when using healthcare services has been nuanced by new research. This shows that language preferences are individual and situational. Parts of the literature emphasise the importance of kinship and self-help traditions.⁷

There is an ongoing project ([Public dementia care in terms of equal services – family, local and multiethnic perspectives](#)) into how Sámi dementia sufferers perceive and use the welfare services in Norway.

Over the past few years, the public institution Norwegian National Advisory Unit on Ageing and Health has: run a [number of](#)

⁷ Blix, B. H.: *Helse- og omsorgstjenester til den samiske befolkningen i Norge – En oppsummering av kunnskap*. 2016.

informational initiatives about dementia and dementia amongst Sámi people in Norway; and, developed various tools. Materials are available in four languages – north Sámi, Lule Sámi, south Sámi and Norwegian.

Ahead of 1 January 2019 and the coming into force, in **Sweden**, of reinforced legislation on national minorities and minority languages, the government asked the National Board of Health and Welfare to map out any need for knowledge resources in healthcare and social services.⁸ This **mapping out**, which is not specifically directed towards services for people with dementia, sets out that: Sweden's "Minorities Act" and the national minority issues are given low priority by management and personnel in Swedish municipalities and regions; there are preconceptions; and, there is a lack of understanding regarding why the national minorities have specific rights. The provisions of the "Minorities Act" are interpreted differently by different municipalities, regions and representatives of the national minorities. In all areas of operations, there is a shortage of personnel with skills in minority languages and cultures. The demand for support and services in minority languages in certain areas is limited or varies over time. This makes it difficult for municipalities and regions to offer a stable range of social and healthcare services in minority languages. The mapping out details a number of measures directed at the target groups. However, the situation varies widely between the municipalities.

In 2017, the Swedish regions of Norrbotten, Västerbotten, Jämtland Härjedalen (in South Sámi: Jiemhten Herjedaelien Dajve) and Dalarna initiated the "**Knowledge network for Sámi health**" project. In 2018, the Sámi parliament in Sweden instituted a board for "health, ageing and sport". This works closely with the aforementioned knowledge network. In collaboration with the Sámi parliament and Sámi organisations, the network has produced a **draft national strategy for Sámi health**. Geriatrics is one of the five prioritised care areas in said draft.

⁸ *Behovet av kunskap om den stärkta minoritetslagen. En kartläggning av behovet av kunskapsstöd inom socialtjänsten (särskilt äldreomsorgen) och hälso- och sjukvården om lagen (209-724) om nationella minoriteter och minoritetsspråk.* Socialstyrelsen [National Board of Health and Welfare in Sweden]. 2019.



In **Finland**, the Improving the brain health of ethnic minority elderly (ETNIMU) project has developed national operating models and in-depth knowledge of memory and memory disorders amongst ethnic minorities in general. For social and healthcare professionals and students, the project has also provided in-depth knowledge about initiatives in the target group.

The Finnish state provides certain support for Sámi social and healthcare services. This is administered via the Sámi parliament, which has established goals for the provision of social and healthcare services in the Sámi language. However, reports from 2001 and 2008 showed that access to social and healthcare services in Sámi was still inadequate, even in the municipalities. As in other Nordic countries, Sámi-speaking patients in Finland encountered problems with various forms used in various tests (e.g. memory testing). Said forms use terms that are not known, or are irrelevant, to elderly Sámi.⁹

The Finnish institute for health and welfare (THL) has initiated [a project for equality in the provision of welfare for Sámi people](#). Finland's SámiSoster organisation has also carried out several development and pilot projects. It offers home-help services in Sámi in the municipality of Enontekiö. In 2017, said organisation won a European prize for its work. This included a project aimed at supporting Sámi dementia sufferers by satisfying cultural and linguistic needs via music, handicrafts and "re-establishing contact with nature".

The government of **Greenland** decided on a national dementia strategy in 2013, based on a 2012 investigation.¹⁰ Although still in force, the strategy is somewhat outdated. Responsibility in the area of dementia rests with the Ministry of Health, which monitors dementia strategy implementation in the municipalities and in the operations of the public healthcare authority (Sundhedsvæsenet). The 2012 investigation shows that approximately 250 people in Greenland have a dementia diagnosis.

In 2019, the research and development project Arktisk aldring ("Arctic Aging", AgeArc) published a comprehensive description of

⁹ Magga, R.: [Saamelaisten sosiaali- ja terveyspalvelujen kehittämisen haasteet Suomessa](#). Yhteiskuntapolitiikka 75 (6). 2010.

¹⁰ [Demensredefølse 2012](#). Departementet for sundhed. 2012.

elderly people's living conditions in Greenland. The report¹¹ is based on a population survey from 2018 and a broad ethnographic interview material. It shows that many relatives of people with dementia, but not all, experience a lack of communication and information from authorities and municipalities. There are large differences between the municipalities in the knowledge of dementia and good dementia care for the health care staff, and there is also a great need for information on dementia in the population. The report recommends a national knowledge bank and sparring partner for Greenland's municipalities. Such an institution could keep an overview of what resources are available in the individual municipalities.

All dementia examinations are being carried out at Greenland's national hospital ("Queen Ingrid's Hospital"). Here, neurologists, nurses and physiotherapists are carrying out work in the field of dementia. However, the authorities are seeking to make it possible for the majority of dementia studies to be carried out locally. The Rowland Universal Dementia Assessment Scale (RUDAS) was translated into Greenlandic in 2019 and is now to be validated. Greenland's first national conference on dementia is planned for 2020. The Ministry of Health, the Ministry of Social Affairs and Justice and researchers from an Arctic, ageing-related project are to be the organisers.¹²

An indigenous people's perspective of Nordic dementia collaborations

Since 2015, the Nordic Welfare Centre has coordinated a Nordic dementia network for experts and public authority representatives in the constituent countries. As its starting point, the network uses the national strategies and guidelines available in the field of dementia.

From 2013 to 2017, the Nordic Welfare Centre coordinated, at the request of the Norwegian Directorate for Children, Youth and Family Affairs (Bufdir), the [Sámi people with disabilities](#) project. This was

¹¹ Nørtoft K. et.al.: *Aldre menneskers liv og helbred i Grønland. En rapport fra forsknings- og udviklingsprojektet Arktisk Aldring (AgeArc)*. 2019.

¹² Announcement by Mikaela Augustussen, Ilisimatusarfik (University of Greenland), in a presentation to the Nordic dementia network, April 2019.

based on there being little knowledge about disabled people with a Sámi background in the Nordic countries. The project resulted in a pilot study, five research reports and a project report that contained policy recommendations.¹³

In 2017, researchers, municipalities and other bodies in the Nordic countries requested that the Nordic Welfare Centre should highlight the indigenous peoples aspect in the dementia field too. Collaborating with Region Jämtland Härjedalen and Staare 2018 (the event celebrating a Sámi centenary), the Nordic Welfare Centre held the first Nordic conference on indigenous peoples and dementia in autumn 2018. The venue was Östersund (Staare in South Sámi). Over 90 researchers, civil servants (at national, regional and municipal levels), municipal care and welfare professionals and representatives of civil society attended.

The conference participants agreed that the Nordic welfare systems had good things that could be built on. For example, there are Sámi schools, preschools and childcare facilities in many municipalities in Sweden and Norway. There is also Sámi elderly care. "Sámi" here means that the Sámi language is used and that operations are run in a way that matches Sámi culture. Over the past few years, the development towards so-called person-centred elderly and dementia care has meant that a major part of care is based on the individual and the individual's background, interests and abilities. Consequently, the Sámi perspective has a natural place in Sámi areas and for people with a Sámi identity. To a large extent, this also takes in those close to care recipients.

¹³ Huuva K. et al.: *Kunskapsläge: Personer med funktionsnedsättning och samisk bakgrund*. Nordens välfärdscenter 2014. Melbøe L. et al.: *Situasjonen til samer med funksjonsnedsettelse*. Norges arktiske universitet og Nordens velferdssenter. 2016. Uttjek, M.: *Levnadsförhållanden bland samer med funktionsnedsättning i Sverige*. Umeå Universitet och Nordens välfärdscenter 2016. Gjertsen H. et al.: *Kartlegging av levekårene til personer med utviklingshemming i samiske områder*. Norges arktiske universitet og Nordens välfärdscenter. 2017. Edin-Liljegren A. and Flykt K.: *Förutsättningar och villkor för samer med funktionsnedsättning i de samiska förvaltningskommunerna i Sverige*. Glesbygdsmedicinskt Centrum [Centre for Rural Medicine], Västerbotten läns landsting og Nordens välfärdscenter. 2017. Hokkanen L.: *Experiences of inclusion and welfare services among Finnish Sámi with disabilities*. Nordic Welfare Centre. 2018. Dahlberg A. & Bergström J.: *Slutrapport: Personer med funksjonsnedsettelse med samisk bakgrunn*. The Nordic Welfare Centre. 2018. Bergström, J.: *Personer med funktionsnedsättning och samisk bakgrund. Policyrekommendationer*. Nordens välfärdscenter. 2018.

In spring 2019, after the Östersund (Staare) conference, a new Nordic network was established in the field of indigenous peoples and dementia. It comprises public authority representatives, researchers and care and welfare professionals in Finland, Norway, Sweden and Greenland. This network is one of three subnetworks in the Nordic dementia network. The aim is a collaborative identification of needs for: new research; expertise-enhancing measures; and, translation/adaptation of diagnostic tools (to Sámi and Greenlandic languages and cultures).



Challenges and proposals emerging from workshop groups at the first Nordic conference on indigenous peoples and dementia

Challenge 1:

Municipalities and rights holders have insufficient knowledge of rights and what they entail

- The rights-establishing legislation comprises framework acts that are not taken sufficiently seriously by the municipalities and which do not give the municipalities concrete tools or define their responsibilities clearly enough. Many municipalities work on a “same for all” principle. In practice, this means that the welfare services are the same, but not equal.
- Restrictions on language and ethnicity registers make it difficult for the municipalities to “find” Sámi people. Major urban municipalities that support diversity initiatives and projects run by civil society do not thereby support Sámi organisations (this is because the Sámi are not in the target group for “integration”).
- “Dementia” may not necessarily “exist” for (old) Sámi and Inuit people, or it may be defined as something other than illness. Many elderly Sámi people cannot read or write Sámi. Consequently, they cannot use written information in their own language. More people with autochthonous backgrounds need to know about their rights, what it means to live in a Sámi administrative district and what rights legislation gives to citizens who do not.

Proposals

1. National guidelines and ordinances on care and welfare for people with dementia must take up an indigenous peoples perspective and the practical consequences of this (e.g. mother tongue, use of interpreters, lifeworld perspectives, cultural concepts, sensitivity and so-called cultural safety). Dementia teams, support administrators and other representatives of the municipalities should have a clear assignment to communicate what the individual citizen is entitled to under national legislation on indigenous peoples and minorities.
2. Sámi administrative districts need guidelines, guides or other forms of support (developed at a national level) for how rights legislation can be implemented in practice. National, regulatory authorities should design and offer concrete information measures that can be used by Sámi administrative districts. Said measures should cover the Sámi in general and, more concretely, their rights and how individuals can complain if the rights are not honoured.
3. One initiative at a Nordic level may be to map out and compare relevant rights legislation and local implementations of this in Norway, Sweden, Finland, Greenland and, possibly, Denmark.

Challenge 2: Lack of linguistic and cultural expertise in the municipalities

- When recruiting personnel, Norwegian and Swedish municipalities often do not ask for a knowledge of Sámi language and culture. In Greenland, there is a lack of personnel who understand and speak Greenlandic.
- In Norway, there are nursing courses that have literature with a Sámi perspective. Research presented at the conference¹⁴ showed that only one of these courses has a special and purposefully designed content on Sámi thematic in their teaching program. In Finland, a Sámi language and culture project were carried out in an individual social welfare and nursing course. However, a Sámi perspective is generally invisible in Sweden's and Finland's courses in the field of health, medicine and social work.

Proposals

1. The municipalities need to systemise their recruitment of personnel with expertise in Sámi language and culture. A start towards this may be for job adverts to state that the recruiter looks forward to receiving interest from Sámi applicants (a practice adopted by the Swedish municipality of Strömsund or, in South Sámi, Straejmien tjjelte). The municipalities should even create new qualification, career and salary possibilities for personnel with relevant linguistic and cultural skills.
2. There is a need for: knowledge-based material on traditional Sámi and Inuit views of dementia; and, qualification-enhancing certification of care personnel who are skilled in Sámi or Inuit culture. This latter could, for example, work along the lines of [Silviahemmet certification](#) in Sweden. A basic, practice-oriented course in Sámi culture could be developed for all employees in the care, welfare and social services field in Sámi administrative districts. Such a course

¹⁴ Eriksen, L. T., Bongo, B. A. & Mehus, G.: [Urfolksperspektiv i utdanning. Sykepleierutdanning i Norge uten urfolkskunnskap?](#) *Nordisk Sykeplejeforskning* 7 (3). 239-249. 2017.

should ask and answer seemingly banal questions such as
“What is a Sámi?” and “Do Sámi people live in large towns?”

Challenge 3: Lack of tools for everyday work and tools for development of operations

- Some tools have been developed in Norway (e.g. for diagnostics and information to those close to dementia sufferers). However, in all Sámi languages and Greenlandic, there is still a severe shortage of culturally adapted and/or translated tools.

Proposals

1. One initiative at national and Nordic levels may be to establish annual arenas where managers and other personnel in the administrative districts can meet and exchange findings.
2. Another (also possibly national or Nordic) may be to identify tools that are already used in Nordic countries. It would also be good to identify any relevant networks, tools and methods developed for the traditional so-called national minorities in the Nordic countries (e.g. Tornedalians, Sweden Finns, Kven people and Jewish people). Such mapping outs could also cover municipal initiatives such as homes or day care facilities that cater for the elderly and have a Sámi profile. A systematic collation of narratives from those close to dementia sufferers could also be used as a basis for developing municipal operations. Successful municipal initiatives could additionally be collated in a digital, Nordic toolbox that could be disseminated via existing, national, centres of dementia expertise.

Challenge 4: How to further develop Nordic collaborations on indigenous peoples and dementia

- As part of the official, Nordic collaboration on dementia, there needs to be a Nordic subnetwork on dementia and indigenous peoples. This should have stable, long-term financing. Said subnetwork should identify relevant forms for systematic collaborations with the Sámi parliament and with bodies in Greenland.
- The subnetwork could take a leading role in identifying resources such as diagnostic tools, checklists and so on that could be translated and adapted for use in several Nordic countries (see above). Similarly, the network could have a role in identifying and proposing solutions to new needs (e.g. tools and methods adapted to younger people with dementia and autochthonous backgrounds).

Proposals

1. There needs to be a Nordic mapping out of existing Nordic and international research into dementia and indigenous peoples. Centred on including such mapping out in the Nordic countries' knowledge portals, the subnetwork could start a dialogue with national authorities. The subnetwork could also review possibilities for stimulating Nordic collaboration around research (e.g. research into effects of various initiatives or a scientific mapping out of needs). Additionally, collaboration with the international research network for indigenous peoples and dementia could be explored.
2. The subnetwork and the Nordic Welfare Centre should identify opportunities for developing Sámi and Greenlandic perspectives of existing Nordic collaboration centred on telecare (e.g. by including municipalities in Greenland or Sámi administrative districts in Norway, Sweden and Finland).



Literature

This list includes only literature that was presented at the conference or was used as input for the presentations given there.

Anderson, Ian et al.: Indigenous and tribal peoples' health (The Lancet-Lowitja Institute Global Collaboration). A population study. *The Lancet* 388. 2016.

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Warren, L. A. et al.: Prevalence and incidence of dementia among indigenous populations: a systematic review. *International Psychogeriatrics* 27 (12). 2015.

National policy documents and web resources

- [Norway's Dementia Plan](#)
 - [Sweden's dementia strategy](#)
 - [Finland's National Memory Programme](#)
 - [Greenland's draft dementia plan](#)
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- ["Ageing and health \(Norway\), Tools and information for and about the Sámi people and dementia"](#)
 - ["What is dementia?"](#), easy-to-read information about dementia (adapted for people with cognitive impairments – available in North Sámi, Lule Sámi, South Sámi, five Nordic languages and English).
 - [Nordic dementia network](#)
 - [Subnetworks within the field of dementia](#)



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