

DANISH DEMENTIA RESEARCH CENTRE

Copenhagen Memory Clinic and
National Information & Education Centre for Dementia



DANISH DEMENTIA
RESEARCH CENTRE

The seahorse in the DDRC's logo resembles an area of the brain shaped like a seahorse, which is why it is called the hippocampus (Latin for seahorse). This area of the brain plays an important role in memory.



DANISH DEMENTIA
RESEARCH CENTRE



Rigshospitalet

PREFACE

It is a pleasure to present the 2020 annual report for the Danish Dementia Research Centre (DDRC) with an overview of the activities in our memory clinic and research groups as well as in our national educational programs.

Indeed, 2020 was a challenging year not only for DDRC, but first and foremost for people with dementia and their caregivers, due to the COVID-19 pandemic. More than 25% of Denmark's deaths with COVID-19 were people living in nursing homes, the majority of whom were people with dementia. In line with international reports, a diagnosis of dementia was associated with 25% mortality risk from COVID-19. The quality of life of people with dementia in nursing homes also suffered from long-term social isolation.

In 2020 DDRC moved to a new building at Rigshospitalet, an excellent environment for our memory clinic and the biobank and neurogenetics research laboratory, and for our research, communication, educational and administrative teams.

Facing the public park Fælledparken, the ground floor will be the home for our new "Innovation and living lab" with a dementia friendly exhibition and garden. The new building also offered the opportunity to open a new "Clinical trial unit" with dedicated space for our drug trials in Alzheimer's disease and Huntington's disease as well as investigator initiated clinical studies.

For the DDRC 2020 was a challenging year, most administrative and research meetings were converted from face-to-face to virtual format and many employees have been working from home. During the Spring of 2020 most patient visits were also converted to other formats or cancelled. Clinical research studies and our national projects involving the recruitment of professional care staff, patients or caregivers, were on hold for a

long period of time and will be delayed. Many of our courses and conferences, including the Dementia Days ("DemensDagene") were cancelled due to COVID-19 restrictions.

However, we were also inspired by the consequences of the pandemic – in developing new ways of communication with our target groups – for instance new ways of engaging the students in online courses. In 2020 we launched a new addition to our ABC Dementia e-learning program "ABC Dementia – Challenging Behavior". The DDRC authored or co-authored 61 scientific papers, books or book chapters in 2020, including a new European Academy of Neurology guideline on medical management issues in dementia, initiated by DDRC and many interesting original scientific results – listed in "publications".

Our achievements in patient care, research and education would not be possible without the support from our Danish and international collaborators and scientific advisors. We would like to thank the Danish Ministry of Health and the Elderly and public and private foundations (listed in "acknowledgements") for financial support to our activities.



Gunhild Waldemar
Professor and chair of DDRC

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Nerve- og Muskelsygdomme, klinik
Copenhagen Neuromuscular Center
Neuromuskulær Forskningsenhed

ETAGE

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Hjerne- og Nervekirurgi, klinik
Neurobiologisk Forskningsenhed, Laboratori

ETAGE

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Neurobiologisk Forskningsenhed

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Center for Hørelse og Balance

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Center for Hørelse og Balance

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Hukommelsesklinikken
Forskningslaboratorium

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Hukommelsesklinikken
Klinisk Forskningsenhed

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Nationalt Videnscenter for Demens

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Omklædning Damer 4
Omklædning Herrer 3
Neurobiologisk Forskningsenhed, MR øveska

corona | COVID-19

Vi anbefaler brug af
MUNDBIND
i elevatoren

Mundbind udleveres
Informationen i forhallen

ABOUT THE DANISH DEMENTIA RESEARCH CENTRE

ORGANISATION

Located at Rigshospitalet and based in the Department of Neurology, the Danish Dementia Research Centre (DDRC) comprises three sections:

- Copenhagen Memory Clinic
- Dementia Research, Clinical Trial Unit (CTU) and Neurogenetics Research Laboratory
- National Information and Education Centre for Dementia

The Copenhagen Memory Clinic is a secondary and tertiary referral-based multidisciplinary out-patient clinic offering diagnostic evaluation and treatment of patients with cognitive disorders and dementia. The CTU conducts sponsored clinical drug trials in neurodegenerative disorders and investigator initiated clinical studies. The Research Laboratory comprises clinical research groups, a neurogenetic research laboratory and the Danish Dementia BioBank.

Initiated and funded by the Danish Ministry of Health, the National Information and Education Centre for Dementia has a steering committee and a scientific advisory board to guide and overview our mission:

- To strengthen and coordinate health research in relation to specific treatment and care interventions in clinical practice.
- To assure national dissemination and communication of knowledge in collaboration with Danish regions and municipalities.

With representatives from the Ministry of Health and the Elderly, Danish Regions, Local Government Denmark, Capital Region, and Rigshospitalet, the steering committee monitors the strategic development and performance of the National Information and Education Centre according to predefined objectives and milestones, as outlined in our strategy for 2016-2020.

In 2020 a new strategy 2021-2025 was developed together with our collaborators and stakeholders.

The scientific advisory board reviews and contributes with advice on major educational and scientific activities.

The members of the advisory board represent the Danish Health Authority (SST), municipalities in Local Government Denmark, Danish Regions, Danish College of General Practitioners, the Danish Alzheimer's Association, the Danish Huntington's Disease Association and the DaneAge Association.

In 2020 the chairman of the steering committee Svend Hartling (Vice-president, Capital Region of Denmark) retired, and Kurt Espersen (Vice-president, Region of Southern Denmark) was appointed chair. For an updated list of members of the steering committee and advisory board, see www.videnscenterfordemens.dk.

VISION

Our vision, "A longer life without dementia – a better life with dementia," provides us with the focus needed to accomplish our goals in finding solutions for prevention of cognitive decline and for improving health care for the benefit of people with dementia.

VALUES

Our four key values serve to guide our priorities and organisational decisions.

High quality: Highly ambitious, we constantly strive to reach the highest professional standards, professionalism and innovation with regard to the development of our services.

Commitment: Our commitment is reflected in our work and our dedication to the goal of preventing dementia and improving the quality of life for patients with dementia and their caregivers.

Respect: We show respect for patients, caregivers, professionals and collaborators and for the ethical challenges related to caring for people with dementia. We are dedicated to understanding, including and meeting their needs.

Transparency: We assure transparency about our goals, methods and results and with regard to our professional relationships.

SPECIAL EVENTS 2020

The Danish Alzheimer Research Foundation Clinical Prize

The Danish Alzheimer Research Foundation Clinical Prize was in 2020 awarded to neuropsychologist, Associate Professor, Ph.D. Asmus Vogel from the Danish Dementia Research Centre. The nomination was a recognition of extraordinary research in cognitive dysfunction in dementia diseases. The prize ceremony takes place as an annual event in relation to the International Alzheimer's day in September and the prize is awarded to researchers that have made a significant contribution to the lives of people living with dementia and their caregivers. The prize was presented by HRH Princess Benedikte.



PhD defense by Le Gjerum

In September Le Gjerum, MD, was awarded her PhD after defending her thesis: "Optimizing ¹⁸F-FDG-PET in the diagnosis of dementia disorders".

In the Assessment Committee were:

Rigmor Højland Jensen, professor, MD, DMSc (chairperson), Department of Clinical Medicine, University of Copenhagen, Denmark, Per Borghammer, professor, MD, PhD, DMSc, Department of Clinical Medicine – Nuclear Medicine and PET, Aarhus University, Denmark and Ruben Smith, associated professor, MD, PhD, Lund University Research Groups, Department of Clinical Sciences, Malmö, Sweden

The supervisors were: Steen Gregers Hasselbalch, professor, MD, DMSc (principal supervisor), Danish Dementia Research Centre, Department of Neurology, Rigshospitalet, University of Copenhagen, Denmark, Ian Law, professor, MD, PhD, DMSc (primary co-supervisor), Department of Clinical Physiology, Nuclear Medicine and PET, Rigshospitalet, University of Copenhagen, Denmark, Kristian Steen Frederiksen, MD, PhD (co-supervisor), Danish Dementia Research Centre, Department of Neurology, Rigshospitalet, University of Copenhagen, Denmark and Otto Mølby Henriksen, MD, PhD (co-supervisor), Department of Clinical Physiology, Nuclear Medicine and PET, Rigshospitalet, University of Copenhagen, Denmark

New Clinical Trials Unit

In 2020 the DDRC established a new Clinical Trials Unit (CTU) in our new building. Located next to the memory clinic, the CTU has dedicated facilities for clinical drug trials in patients with neurodegenerative disorders, as well as investigator initiated studies. At the same time senior neurologist Kristian Steen Frederiksen was appointed director of the CTU.





WHO prize for Research in Health Care for the Elderly and in Health Promotion

In 2020 DDRRC chair, professor Gunhild Waldemar received the WHO prize for Research in Health Care for the Elderly and in Health Promotion (also named State of Kuwait – His Highness Sheikh Sabah Al-Ahmad Al-Jaber Al-Sabah Prize 2020). The prize is awarded each year at the WHO general assembly to a person or persons, an institution or institutions, or a nongovernmental organization or organizations who have made an outstanding contribution to research in the areas of health care for the elderly and in health promotion.

Gunhild Waldemar was awarded the prize for her “substantial contributions to research in health care for older adults, including in the areas of dementia diagnosis, inappropriate use of opioids and antipsychotics in older adults with dementia, the effect of early psychosocial counselling and support and the effect of exercise in people diagnosed with Alzheimer disease. She has actively contributed to the advancement of health care and quality of life of people with dementia through the development and implementation of different programmes and policy related activities” in Denmark and internationally.

Due to COVID-19 pandemic the 2020 WHO general assembly took place as an online event, and the award was celebrated at the Danish Health Authority in June 2020 with the participation of WHO regional director for Europe dr. Hans Kluge, Danish Minister of Health and the Elderly Magnus Heunicke, and director of the Danish health authority dr. Søren Brostrøm.



The Lundbeck Foundation 2020 Talent Prize

Christian Sandøe Musæus, MD, received the Lundbeck Foundation 2020 Talent Prize for his research in dementia. Currently, Christian Sandøe Musæus is a ph.d.-student at the Danish Dementia Research Centre and University of Copenhagen. Since 2013 while still studying medicine at the University of Copenhagen, he has been conducting research in EEG markers for Alzheimer’s Disease and other forms of dementia. Electroencephalography (EEG) is an inexpensive and non-invasive imaging technique. In a large multicentre study with colleagues from Denmark and other Nordic countries he found that EEG may be a promising classifier of disease and a marker of progression in early Alzheimer’s disease.

In his PhD-project, he uses a new type of EEG equipment, so called ear EEG, which is a small device to be inserted into the ear, pretty much like a hearing aid. The patients wear the earpiece at home for a few days while the device registers and stores information from activity in the brain, including epileptic activity.



COPENHAGEN MEMORY CLINIC

Established in 1995, Copenhagen Memory Clinic at Rigshospitalet is a secondary and tertiary referral-based multidisciplinary out-patient clinic. It offers diagnostic evaluation and treatment of patients with cognitive disorders and dementia. We receive referrals from general practitioners, private practice neurologists, psychiatrists and other hospitals in the Capitol Region of Denmark. Patients may also be referred from other memory clinics for second opinion evaluations.

A satellite memory clinic is located on the island of Bornholm. For both sites, general practitioners, hospital departments and private practice specialists from local catchment areas can refer new patients for diagnostic evaluation of cognitive, behavioural or other symptoms suggestive of dementia or cognitive disorders. A dedicated multidisciplinary team of consultant neurologists, psychiatrists, geriatricians, neuropsychologists, specialist nurses, a clinical geneticist, a social counsellor and medical secretaries manage diagnostic evaluation and treatment.

In the spring of 2020 the memory clinic was partly closed for several weeks due to the COVID-19 pandemic. Video or telephone consultations with selected patients and their caregivers replaced consultation visits.

DIAGNOSTIC EVALUATION AND PLAN FOR TREATMENT AND CARE

The majority of patients undergo a standard set of examinations and procedures, beginning with a detailed medical history. Cognitive functions are then assessed with the Mini-Mental State Examination and the Danish version of Addenbrooke's Cognitive Examination. Physical and neurological/geriatric assessments, routine laboratory tests, ECG and structural CT or MRI of the brain are also performed. Other supplemental investigations are performed when clinically relevant, for example: fludeoxyglucose positron emission tomography (18FDG-PET) and amyloid PET, neuropsychological assessment, routine and biomarker examination of cerebrospinal fluid (CSF), EEGs and psychiatric evaluations. After completion of the initial examinations and procedures, the multidisciplinary team prepares a

Table 1. Classification of new patients who completed a diagnostic evaluation programme in 2020

SYNDROME	DIAGNOSIS	BLEGDAMSVEJ	BORNHOLM	TOTAL
Dementia		898	71	969
	Alzheimer's disease	440	32	472
	Vascular or mixed dementia	187	23	210
	Dementia with Lewy bodies, Parkinson's disease with dementia, Parkinson-plus syndromes	73	4	77
	Frontotemporal dementia	30	3	33
	Other specific conditions, including Huntington's disease and normal pressure hydrocephalus	71	1	72
	Dementia of uncertain aetiology and alcohol-related dementia	97	8	105
Mild cognitive impairment and other cognitive profiles	Patients with specific neurodegenerative disorders without dementia; patients with depression and other psychiatric conditions and sequelae after traumatic brain injury	422	25	447
No cognitive impairment	Patients with subjective symptoms and no significant pathology	345	2	347
Genetic counselling	Family members of patients with familial neurodegenerative conditions referred for genetic counselling	176	-	176
All completed evaluations (excluding genetic counselling)		1665	98	1763



In the Copenhagen Memory Clinic we perform lumbar puncture as part of the diagnostic work-up of patients suspected of neurodegenerative diseases.

standardised consensus report containing a classification of the cognitive profile, the primary underlying cause, concomitant conditions and a treatment plan. Following the consensus meeting, the patient and caregivers are invited to meet with the specialist physician and specialist nurse, where information and counselling is given on diagnosis and on the treatment and care plan. A short summary is subsequently sent to the patient's general practitioner and community nurse, where relevant.

SPECIALISED MEDICAL SERVICES

Patients with rare, complex or familial disorders may be referred from other parts of Denmark (mainly Eastern Denmark) for treatment and follow-up. Genetic counselling and testing is also offered for healthy at-risk family members.

In accordance with guidelines for local, regional and highly specialised medical services from the Danish Health Authority, Copenhagen Memory Clinic has been approved as a regional or highly specialised centre in the fields of dementia and neurogenetics for the following services:

- Second opinion evaluations of patients with possible dementia and dementia with uncertain aetiology
- Diagnosis and treatment of developmental disorders with dementia
- Diagnosis and treatment of frontotemporal dementia

- Diagnosis and treatment of rare and late-onset hereditary neurodegenerative diseases, for instance: Alzheimer's disease (AD), frontotemporal dementia (FTD), spinocerebellar ataxias (SCA) and Huntington's disease (HD)
- Clinical evaluation, lumbar perfusion and tap tests for patients with suspected normal pressure hydrocephalus (NPH)

The highly specialised services are performed in collaboration with several other specialist departments at Rigshospitalet, for example: the Department of Clinical Genetics; the Department of Neurosurgery; the Department of Neuropathology; the Department of Clinical Neurophysiology; the Department of Neuroradiology; and the Department of Clinical Physiology and Nuclear Medicine (the PET and Cyclotron Unit, Rigshospitalet). A monthly clinical conference is held with specialists from the imaging (MR and PET) departments and four annual patient conferences are held with the Movement Disorders Clinic at Bispebjerg Hospital (cancelled in 2020 due to the COVID-19 pandemic).

Normal pressure hydrocephalus (NPH)

Diagnostic evaluation of NPH is a complex task. The patients often have multimorbidity and characteristic symptoms such as: gait disturbance, urinary incontinence and cognitive decline, which are also common to various other

diseases. Most patients are referred for possible NPH because their CT or MRI demonstrated a dilated ventricular system. In 2020 there were 322 patients referred for a clinical evaluation of NPH, 113 of whom had a lumbar perfusion test and/or Tap Test after the clinical examination. All patients are discussed at a weekly conference with the NPH team at the Department of Neurosurgery, Rigshospitalet. The treatment, which can involve insertion of a shunt to drain excess CSF from the brain, may reverse some of the symptoms and restore functioning.

Genetic counselling

The Copenhagen Memory Clinic offers a programme for healthy at-risk family members from families with confirmed or suspected late-onset familial neurodegenerative diseases referred for clinical genetic evaluation and counselling. This service is executed in collaboration with the Department of Clinical Genetics at Rigshospitalet and includes an evaluation by our specialist in clinical genetics, as well as a consultation with a trained psychologist before genetic testing is considered. In 2020 there were 102 at-risk family members referred. The clinic also offers post-genetic test counselling when needed.

FOLLOW-UP PROGRAMME FOR PATIENTS AND FAMILIES

All patients with mild cognitive impairment (MCI), and selected groups of patients with dementia or specific neurodegenerative disorders are offered counselling and follow-up in collaboration with primary health care. Patients with conditions of uncertain aetiology and healthy mutation carriers may also be offered follow-up in the memory clinic. The majority of patients in the follow-up programme have MCI, AD, dementia with Lewy bodies (DLB), FTD, HD, SCA, NPH, Down's syndrome with dementia or other neurodegenerative/neurogenetic conditions. Most patients are accompanied by their family caregivers when visiting the clinic, and we offer counselling for the caregivers as an integral part of the follow-up programme. For fragile patients with severe dementia home visits are offered.

Copenhagen Memory Clinic in 2020

- 1,695 new patients
- 12,142 patient visits or virtual visits

Bornholm Memory Clinic in 2020

- 104 new patients

4,695 patients are in a follow-up programme.

As part of its services the clinic offers courses for patients and caregivers, which have been cancelled in 2020 due to the COVID-19 pandemic.

BORNHOLM MEMORY CLINIC

Led by the Copenhagen Memory Clinic, the outpatient clinic is located at the internal medicine department on Bornholm's Hospital. A team of one consultant neurologist and one neuropsychologist from the Copenhagen Memory Clinic, together with a nurse and a medical secretary from Bornholm's Hospital offers consultations one day per week for patients on Bornholm. On one additional day per week a resident in geriatrics see patients under the supervision of a neurologist from the Copenhagen Memory Clinic using video-consultation. The Copenhagen Memory Clinic has also contributed to educational services for health care professionals on Bornholm.

REGIONAL AND NATIONAL COLLABORATION

In 2011 the Capital Region established a guideline ("forløbsprogram") for coordinating patient care pathways between hospital-based memory clinics, mental health centres, other hospital departments, general practitioners and primary health care in its 29 municipalities. An update of the guideline was completed in 2020.

For patients from the City of Copenhagen ("planområde BYEN"), Copenhagen Memory Clinic has specific collaboration programmes with the Departments of Geriatrics and Palliation at Bispebjerg Hospital, psychiatric departments (Mental Health Centre Copenhagen), general practitioners, and the care institutions and home care in the City of Copenhagen and the City of Frederiksberg. We also collaborate with geriatric and psychiatric departments as well as general practitioners and the 10 local authorities in the southern part of the Capital Region ("planområde SYD").

In 2016 the national quality registry for dementia was launched, based partly on a previous regional version from the Capital Region established in 2006. The registry, which includes data from approximately 40 memory clinics in Denmark, is monitored by a national steering committee. The Copenhagen Memory Clinic contributes to the registry. is also an active member of the Network of Danish Memory Clinics, coordinated by DDRC.



RESEARCH AT DDRC

The DDRC research program is focused on epidemiological, clinical and translational research in cognitive impairment and neurodegenerative disorders. The majority of our research is funded by grants and donations from public and private foundations. Here we describe our resources, our thematic areas of research, and the international consortia and networks with whom we collaborate, followed by a presentation of researchers in the “Who is who” section. For updates see www.ddrc.dk (www.videnscenterfordemens.dk).

RESEARCH RESOURCES

Clinical trial unit (CTU) and Trial Nation Denmark

In 2020, a new Clinical Trial Unit (CTU) was established at the DDRC to strengthen the capacity to conduct clinical research including drug trials. The CTU is staffed with a clinical trial director, three research nurses, a research administrator and an additional consultant neurologist. Moreover, additional resources such as nurses, laboratory technicians and medical doctors may be sequestered on an ad hoc basis.

The unit is situated adjacent to the memory clinic, and includes facilities such as dedicated examination rooms, room for i.v. infusions, medicinal storage facilities and a separate waiting area for patients. Lumbar punctures are done on a routine basis. A fully equipped laboratory (centrifuges, fridges and freezers) is also on-site, and close collaboration with the Department of Clinical Physiology and Nuclear Medicine ensures easy access to advanced brain imaging.

The DDRC has more than 25 years of experience with conducting sponsored phase I (“first-in-human”) and phase II-IV drug trials within neurodegenerative dementia disorders including Alzheimer’s disease and Huntington’s disease. The CTU at DDRC is part of Trial Nation Denmark’s Dementia Center. Trial Nation Dementia Center is a governmental initiative which offers a single national entry point for global companies, patient organisations and clinical researchers wishing to conduct clinical trials in Denmark. A total of five memory clinics participate in the network, with DDRC taking on the roles of medial lead and coordinating center offering a one point of access to all memory clinics.

Patient cohorts

Patients with a wide range of diagnostic entities and cohorts of healthy controls and gene mutation carriers serve as the foundation of many DDRC research programs:

- The memory clinic receives approximately 1.500-2.000 new referrals each year. With informed consent from participants, results from diagnostic investigations are stored in a database and form an important basis for research with the aim of improving diagnostic evaluation, treatment and care for memory clinic patients.
- Several large-scale multi center intervention studies (e.g. ADEX, BASIC and DAISY) have been coordinated by DDRC leading to large nationwide patient cohorts with follow-up data. Collaboration on dementia research in selected Danish memory clinics has been established in the ADEX consortium (coordinated by DDRC) – a multi-center Danish research network comprising eight different memory clinics from across the country.
- DDRC is a member of several international networks on familial dementia disorders, such as the European Huntington Disease Network (EHDN) and Frontotemporal Research in Jutland Association (FReJA) which provide platforms for professionals to facilitate collaboration throughout Europe. Such networks also have been instrumental in the recruitment of DDRC patients to pharmacological intervention studies.

Translational Neurogenetics Laboratory

DDRC has an in-house fully equipped laboratory to perform all aspects of cellular and molecular research. We have labs classified for working with genetically modified organisms (class I and class II conditions) in order to work with molecular cloning and viral vectors. Furthermore, we have equipment to perform various standard molecular biological techniques e.g. PCR, quantitative PCR, Western blotting, flow cytometry and fluorescence microscopy. We have set up standard routines for reprogramming fibroblasts into induced pluripotent stem cells and for gene editing using the CRISPR/Cas9 technique and differentiating stem cells into e.g. neurons.

Danish Dementia BioBank (DDBB)

The DDBB contains samples from more than 8.500 patients referred to the Copenhagen Memory Clinic at Rigshospitalet and the Zealand University Hospital Memory Clinic in Roskilde. Whole blood, buffy coat, EDTA plasma and serum are stored for all patients, as well as CSF from approximately 25% of the patients. All samples are handled and stored according to international biobank recommendations.

Danish national registries

All Danish in- and out-patients who have had contact with a Danish hospital are registered in the Danish national health registries with basic information, such as diagnostic codes and procedures. Access to the nationwide health care registries with the possibility of linking to other national registries makes it possible to carry out large population-based studies. These unique national registries have served as the foundation for our studies in dementia including:

- Quality of health care
- Validity of dementia diagnosis
- Pharmacoepidemiology
- Comorbidity
- Mortality in dementia

THEMATIC AREAS OF RESEARCH

Early diagnosis: Neuropsychology and biomarkers

Discovery and validation of early disease markers for AD and other neurodegenerative disorders are key DDRC research areas, which include new biofluid markers, brain imaging and neuropsychology. The biomarker research aims to discover and validate new biofluid markers for the early diagnosis of AD and for the prediction of disease progression, including the use of proteomics and genomics technologies. DDRC conducts and participates in several brain imaging studies on early diagnosis of dementia that contain both structural and functional brain imaging, including studies with amyloid-specific PET tracers. In recent years several studies on comorbidity in early diagnosis have been initiated, including multicentre studies on the role of epilepsy in early dementia and MCI, and new studies analysing the use of ear-EEG to examine epilepsy in AD. Many biomarker studies are carried out in collaboration with other Danish research centres and a wide range of European centres.

Neuropsychological research mainly focuses on characterization of cognitive deficits in the early phase of dementia and MCI. In recent years DDRC has conducted various studies on cognitive processes in aging, as well as longitudinal studies on cognitive deficits and personality traits in gene-expansion carriers. In 2020, data inclusion was completed for a new study on possible changes in self-perception and identity in the earliest phases of neurodegenerative diseases. A validation study for the BASIC cognitive screening test, developed by DDRC and successfully validated in Danish memory clinics, was prepared for launch in a group of general practitioners in Denmark in collaboration with University of Copenhagen, Department of Public Health (Section of General Practice). The performance of BASIC-Q, a version developed for community settings was also published.

Rare causes of dementia and inherited neurodegenerative disorders

Neurogenetic research focuses on clinical characteristics, ancillary investigations and basic research on gene function and therapy. Many neurodegenerative disorders, including Alzheimer's disease, frontotemporal dementia (FTD), Huntington's disease (HD) and ataxias manifest with progressive loss of specific subsets of neurons in the brain. In some diseases genetic mechanisms are involved. Different diseases have different genetic backgrounds, but evidence shows that common neurodegeneration mechanisms may exist. Some of our research focuses on the identification of common molecular mechanisms in neurodegeneration, e.g. in FTD linked to chromosome 3 (FTD3) and spinocerebellar ataxia type 2 (SCA2). We are also exploring the cellular environment in patient-derived cell cultures to pinpoint therapeutic targets.

The FReJA Consortium investigates FTD linked to FTD3, which occurs in a large FTD family in western Jutland. Our research in this disease focuses on the molecular disease mechanism, with neuronal cell lines now derived using stem cell technology to further explore the potential of gene therapy. The DDRC neurogenetics section is a significant international contributor to research in HD, and our large cohorts of patients are assessed with detailed clinical evaluations, genetic markers and CSF profiles. DDRC conducts highly specialized diagnostic examination and treatment of many rare disorders, including normal pressure hydrocephalus (NPH). The DDRC NPH team is currently studying the effect of treatment and diagnostic procedures.



In the Danish Dementia BioBank patient samples are handled in accordance to international procedures. This ensures uniform sample quality for international collaborative research projects.

Public health in dementia

Using nationwide registry data, we have analyzed the quality of health care and use of medication in people with dementia, and time trends in incidence, prevalence and mortality in dementia. The impact of co-morbidity is currently under investigation. As an example, we have been able to demonstrate a significant negative impact of dementia on the risk of hospitalization with dementia. The research is being carried out in collaboration with the National Centre for Registerbased Research at Aarhus University. It is the intention that our research will help provide evidence for creating new guidelines and for DDRRC teaching materials. In fact in 2020 we published a new guideline on medical management issues in dementia – developed under the auspices of European Academy of Neurology in collaboration with distinguished European specialists.

Rehabilitation and psychosocial support

We have extensive experience in carrying out large-scale multicentre studies investigating complex interventions in neurodegenerative diseases. In the ReACT study we examine how assistive technology can be designed to support self-management and rehabilitation of people with dementia. The study also explored methods for implementation and adoption of assistive technology.

Cross-cultural aspects of dementia

To improve diagnostic evaluation and care of ethnic minorities with dementia, the centre has studied the assessment of dementia in various ethnic groups in Denmark and in other European countries, as well as barriers to accessing dementia care. A special interest is the development and validation of cross-cultural cognitive tests and

screening instruments for use in minority ethnic groups in high-income countries, and low and middle-income populations. In the CLEAR study, we focus on developing culturally sensitive programmes for increasing awareness and help-seeking for dementia in minority ethnic groups, as well as programmes for the provision of post-diagnostic care.

INTERNATIONAL CONSORTIA AND NETWORKS

European Alzheimer's Disease Consortium (EADC)

EADC is a network of more than 50 European academic centres of excellence working in the field of AD and other dementias. It provides a forum for expanding scientific understanding and developing ways to prevent, delay, slow or ameliorate the primary and secondary symptoms of AD. The European Commission provided initial funding for EADC and supports working towards standardisation of diagnostic criteria, assessment tools and data collection methods, with a view to a subsequent trial period in-

In DDRC we perform an array of functional and biochemical assays to elucidate molecular pathways in neurodegenerative diseases. The knowledge gained contributes to international consortia.



volving the testing and practical application of the tools agreed upon. DDRC, the only Danish EADC member, has contributed to or directed studies on assessment tools, health economics, biomarkers and cross-cultural aspects of dementia care.

PredictND

PredictND was a four-year, €4.2m European project funded by the EU's 7th Framework Programme that drew to a close in 2018. It focused on developing tools and means for earlier, evidence-based diagnosis of a range of neurodegenerative diseases. PredictND was coordinated by VTT Technical Research Centre of Finland Ltd. (Finland), and the consortium members included Alzheimer Europe (Luxembourg), Combinostics Ltd. (Finland), GE Healthcare (UK, Sweden), Imperial College of London (UK), Rigshospitalet (Denmark), Università degli Studi di Perugia (Italy), University of Eastern Finland (Finland) and VU/VUmc (the Netherlands). The collaboration is still very productive and continues to publish data from the project.

European Huntington's Disease Network (EHDN) and Enroll HD

DDRC is part of EHDN, which provides a platform for professionals and people with HD and their relatives to facilitate collaboration throughout Europe. DDRC's staff and families affected by HD have contributed significantly to clinical cohort studies and intervention studies. Enroll HD, initiated in 2012, is the world's largest observational study for HD families. Designed as a clinical research platform, it enables health care professionals, scientists and families affected by HD to work together towards an improved understanding of HD and better care and treatments. At the end of 2020, DDRC's Enroll HD cohort comprised more than 300 participants.

Frontotemporal Dementia Research in Jutland Association (FReJA)

FReJA is an international multidisciplinary consortium established more than two decades ago to investigate a unique, large FTD-3 family in western Jutland. Basic and clinical scientists in Denmark, Sweden and the UK have made major progress over the years in identifying the disease gene and in understanding the disease mechanisms and their wider relevance for neurodegeneration in general.

BrainStem – Stem Cell Center of Excellence in Neurology

BrainStem – Stem Cell Center of Excellence in Neurology is supported by Innovation Fund Denmark. The project is coordinated by University of Copenhagen, and its

primary partners are DDRC at Rigshospitalet, University of Southern Denmark, Aarhus University, Bioneer, Lundbeck A/S (Denmark), Lund University (Sweden) and Innovative Concepts in Drug Development (France). Advanced stem cell technologies are used to re-programme skin cells from patients with AD and Parkinson's disease to diseased neurons to study the underlying molecular mechanisms in order to develop better diagnostics and to test new drugs.

Interdem

DDRC takes part in Interdem, a pan-European network of researchers collaborating on research and dissemination of early, timely and quality psychosocial interventions aimed at improving the quality of life across Europe for people with dementia and their caregivers. Members of the network include academic and clinical researchers from 23 nations.

Nordic Network in Dementia Diagnostics (NIDD)

NIDD, funded by the Nordic Council, comprises eight academic memory clinics in the Nordic countries and Lithuania. The main objective of the network is to examine various aspects of diagnostic procedures in dementia. One ongoing project involves evaluating quantitative EEG in Dementia diagnostics. DDRC and the Zealand University Hospital Memory Clinic in Roskilde are the network's Danish partners.

Nordic Research Network on Dementia and Ethnicity

The Nordic Research Network on Dementia and Ethnicity comprises researchers with backgrounds in medicine, psychology, occupational therapy, nursing, speech therapy and linguistics who conduct research in dementia and minority ethnic groups. The network currently receives support from the Nordic Welfare Centre.

National dementia research and education centres in Scandinavia

Norway, Sweden and Denmark have national non-profit dementia research and education centres commissioned and funded by the national boards or ministries of health. DDRC, the Norwegian Centre for Dementia Research and the Swedish Dementia Centre collaborate to share ideas and have exchanged programmes for the benefit of professional care staff, people with dementia, and family caregivers throughout Scandinavia.

RESEARCH – WHO IS WHO?

PROFESSORS AND ASSOCIATE PROFESSORS



STEEN G. HASSELBALCH – EARLY DIAGNOSIS, NEUROIMAGING AND BIOMARKERS

Consultant neurologist, clinical professor and research director. Main research interests include diagnosis and pathophysiology of dementia disorders. He has a leading role in several international research collaborations and was the principal investigator in a recent Danish multi-center trial on physical exercise in AD.



JØRGEN E. NIELSEN – INHERITED NEURODEGENERATIVE DISORDERS

Consultant neurologist, clinical professor and research director. Main research areas are genotype-phenotype correlations of inherited neurodegenerative disorders, especially SCA, HD, dystonia, spastic paraplegias and hereditary forms of Parkinson's disease, AD and FTDS.



ASMUS VOGEL – COGNITION AND NEUROPSYCHOLOGICAL DEFICITS

Neuropsychologist and associate professor in clinical neuropsychology. Major research focus is cognitive deficits in dementia diseases. He is initiating and coordinating studies on development and validation of cognitive tests applied in memory clinics.



GUNHILD WALDEMAR – INTERVENTION STUDIES, EPIDEMIOLOGY, GLOBAL HEALTH

Consultant neurologist, clinical professor and chair of DDRC. Main research areas include dementia epidemiology, global health, diagnostic markers, clinical cohort studies and pharmacological and complex interventions.

SENIOR RESEARCHERS



KRISTIAN STEEN FREDERIKSEN – PHYSICAL EXERCISE AND CLINICAL APPLICATION OF AD BIOMARKERS

MD, PhD, consultant neurologist. Serves as clinical trials director and national coordinator and PI for drug trials in AD. Main research areas include the effect of physical exercise and the clinical application of biomarkers in neurodegenerative dementias, with a special focus on brain imaging techniques.



LENA ELISABETH HJERMIND – HEREDITARY MOVEMENT DISORDERS AND NEURODEGENERATIVE DISORDERS

MD, PhD, consultant neurologist. Serves as national coordinator and PI for drug trials in HD. Main research interest is genotype-phenotype correlations and molecular mechanisms in inherited movement disorders and neurodegenerative disorders.



KASPER JØRGENSEN – NORMING, VALIDATION AND DEVELOPMENT OF NEUROPSYCHOLOGICAL TESTS AND CASE-FINDING INSTRUMENTS

MSc, neuropsychologist. Main research focus is norming, validation and development of neuropsychological tests and brief, case-finding instruments for dementia and mild cognitive impairment.



TROELS TOLSTRUP NIELSEN – MOLECULAR MECHANISMS IN NEURODEGENERATION

MSc, PhD and DDRC centre manager. Research focus is on neurodegenerative disorders such as AD, FTD and ataxias. His research centres on finding molecular mechanisms in the inherited neurodegenerative disorder spinocerebellar ataxia type 2 (SCA2).

SENIOR RESEARCHERS



PETER ROOS – CLINICAL AND MOLECULAR ASPECTS OF FTD LINKED TO FTD-3

MD, PhD, consultant neurologist. His research focuses on clinically affected and presymptomatic CHM P2B gene mutation carriers from the Danish FTD-3 family.



ANJA HVIID SIMONSEN – BIOMARKERS AND BIOBANK

MPharm, PhD and director of the Dementia BioBank. Main research focus is molecular and genetic biomarkers for diagnosis and prognosis of neurodegenerative diseases as well as for response to interventions.



LAILA ØKSNEBJERG – ASSISTIVE TECHNOLOGY AND COGNITIVE REHABILITATION

MSc, neuropsychologist. Investigates assistive technology for people with dementia and cognitive rehabilitation in dementia.

POSTDOCS



PATRICK EJLERSKOV – MOLECULAR ASPECTS IN FRONTOTEMPORAL DEMENTIA TYPE 3

Postdoctoral fellow, MSc. Specialist in functional assays involving autophagy and neuroinflammation. His project focuses on describing new molecular pathways causing or contributing to FTD3 pathogenesis with special emphasis on autophagy and neuroinflammation.



CAMILLA STEEN JENSEN – MITOCHONDRIAL DYSFUNCTION IN PATIENTS WITH AD

Postdoctoral fellow, MSc. Research focus on fluid biomarkers in AD. Research area is the mitochondria's dysregulation in the pathogenesis of AD, including molecular assays of the brain's metabolism and functional assays related to mitochondrial stress in patient derived fibroblast cell lines.



ADELE MARTHALER – MODELING SCA2 USING PATIENT-DERIVED INDUCED PLURIPOTENT STEM CELLS (IPSCS)

Postdoctoral fellow, MSc. Investigates the molecular aspects of SCA2 including electrophysiological assays, global RNA sequencing and functional assays related to autophagy and apoptosis.



T. RUNE NIELSEN – CROSS-CULTURAL ASSESSMENT AND DEMENTIA IN ETHNIC MINORITIES

Postdoctoral fellow, neuropsychologist. Main research focus is cross-cultural cognitive assessment and ethnic differences in dementia.

PHD STUDENTS



ANDREAS APPEL
– VACCINATION AND DEMENTIA

His project will investigate the uptake and effect of influenza vaccination on risk of dementia in the elderly population. General effects on hospitalizations and infections will also be studied.



ANNA ELISE BRUUS
– MEMORY IMPAIRMENT IN THE EARLIEST PHASES OF AD

Her project focuses on memory impairment in the earliest phases of AD. Possible changes in autobiographical memory and identity is studied in persons with Subjective Cognitive Decline, MCI and AD.



MARIE NATHALIE NICKELSEN HELLEM
– HUNTINGTON'S DISEASE

Her project investigates the role of neuro-inflammation in the pathogenesis of HD by examining blood and CSF. The aim is also to look for biomarkers and develop HD stem cells.



JANET JANBEK
– ROLE OF INFECTIONS IN DEMENTIA

Her project will focus on the role of infections in dementia. Her project will also investigate the role of infections as risk factors, by taking a life-course approach starting from mid-life.



EMIL ELBÆK HENRIKSEN
– MOLECULAR GENETIC ASPECTS OF SPINOCEREBELLAR ATAXIA TYPE 2 (SCA2)

His project investigates how the genetic mutation in SCA2 affects the mitochondria and the intracellular calcium signaling in stem cell-derived neurons. The outcome of this project will help us understand the disease progression in the early stages.



LÆRKE TAUDORF – DEMENTIA AND MORTALITY: A REGISTER-BASED STUDY

Her project investigates time trends of prevalence, incidence and mortality due to dementia from 1996 to 2015, as well as survival after diagnosis. The project also reviews the registered causes of death in individuals with dementia.



CHRISTIAN SANDØE MUSÆUS
– EPILEPTIC SEIZURES IN AD

His project assesses subclinical epileptiform activity with continuous EEG monitoring using novel ear EEG registration and correlating findings with MRI hippocampal blood flow assessments. Another area of interest is the use of EEG to assist in the diagnosis of AD and MCI.



REBECCA KJÆRGAARD HENDEL
– (NEURO)PSYCHOLOGICAL CHANGES IN HUNTINGTON'S DISEASE GENE-MUTATION CARRIERS

Her project investigates (neuro)psychological changes in Huntington's disease gene-mutation carriers. Focus is on possible impairments in social cognition, apathy on self-perception in the premanifest and early manifest stages.



ANDERS TOFT – CHMP2B-MEDIATED FRONTOTEMPORAL DEMENTIA: MARKERS, MODELS AND MECHANISMS

His project is a clinical follow-up to clarify the role of neuroinflammation in CHMP2B-mediated FTD3. It includes clinical data, inflammatory biomarkers, and generation of patient-specific neuronal and glial cell models to investigate neuroinflammation on a cellular level.

STUDENT RESEARCH FELLOWS (MASTER'S STUDENTS)



CHUQIAO CHEN – DISEASE MODELING OF FRONTOTEMPORAL DEMENTIA (CHROMOS. 3)

Her project investigates molecular mechanisms of FTD-3 mutations including in 1) patient-derived fibroblast, 2) induced pluripotent stem cells and 3) a neuroblastoma knock-out model.



HELENA S. GLEERUP – BIOMARKERS IN SALIVA

Her project investigates whether saliva can be a viable biofluid for the detection of biomarkers of neurodegenerative diseases, especially AD.



MATHIAS HOLSEY GRAMKOW – BIOMARKERS OF NEURODEGENERATION

His project focuses on biomarkers of neurodegeneration including MRI, 18F-FDG-PET and tau in cerebrospinal fluid in the diagnosis and prognosis of patients suspected in dementia.



JULIA GUSATOVIC – NEUROBIOLOGICAL EFFECTS OF EXERCISE

Using diffusion-weighted MRI her project aims to investigate the effects of aerobic exercise on white matter microstructure in patients with Alzheimer's disease



RACHEL UNDERLIEN KRISTENSEN – REGISTER-BASED RESEARCH ON POLYPHARMACY IN DEMENTIA

Her project uses nationwide data to investigate the frequency and time trends of polypharmacy among people with and without dementia to examine potential disparities.



JOHANNE KØBSTRUP ZAKARIAS – EPIDEMIOLOGY AND QUALITY OF DEMENTIA DIAGNOSES

Using nationwide registry data, her project investigated potential geographical variation in diagnostic rate and quality of dementia diagnoses to examine possible inequality in the access to appropriate diagnostic evaluation and care for patients with dementia.

ASSOCIATED RESEARCHERS (CURRENTLY EMPLOYED ELSEWHERE)



ANE NØRGAARD CHRISTENSEN – USE OF PSYCHOTROPIC DRUGS IN PATIENTS WITH DEMENTIA

MD PhD. Her research focuses on the use of antipsychotics and other psychotropic drugs in patients with dementia and investigates the mortality risk associated with the use of psychotropic drugs and a neuroblastoma knock-out model.



CHRISTINA JENSEN-DAHM – EPIDEMIOLOGY AND REGISTER-BASED RESEARCH

MD, PhD. Major research focus is epidemiological studies based on registry data. Current research focuses on medication use (analgesics, anti-dementia drugs, psychotropic medication and polypharmacy) in elderly with dementia.



FREDERIKKE JEPPESEN KRAGH – PHYSICAL ACTIVITY AND ADL FUNCTION

MD Area of interest is different aspects of physical activity and its impact on daily living functions in AD.



KIEU PHUNG – CROSS-CULTURAL DEMENTIA EPIDEMIOLOGY AND PUBLIC HEALTH INTERVENTIONS

MD, PhD. Main research focus is dementia frequency, risk factors and risk modification across different cultures and ethnic groups.



LEA STEVNSBORG – REGISTER-BASED RESEARCH ON DEMENTIA IN IMMIGRANT POPULATIONS

MD. Her project investigates the use of anti-depressants and anti-psychotics in immigrant populations with dementia to identify possible inequalities in access to treatment in immigrant populations.



NATIONALT VIDENSCENTER FOR DEMENS

ÅRSMAGASIN 2020



12 Dør man af demens?

17 Kender du BASIC-Q?



Su Disin

Etha For surfa



Desinficerende uden lugt og effektiv mod bakterier, svampesporer, vira og de fleste vira. Desinficerende egenskaber gør det muligt at bruge på alle typer overflader og i alle typer miljøer. Kan bruges til rengøring af skåle og andre beholdere til brug af fødevarer og drikkevarer. Kan bruges til rengøring af biler og andre overflader. Kan bruges til rengøring af tekstiler og andre overflader. Kan bruges til rengøring af alle typer overflader.

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NATIONAL INFORMATION AND EDUCATION CENTRE FOR DEMENTIA

As a section of Danish Dementia Research Centres, The National Information and Education Centre on Dementia offers nationwide continued education activities, conferences and disseminate information about dementia to professionals. The centre arranges courses, conferences, network meetings, and offers e-learning programmes, apps and printed publications. The centre is also involved in validating and disseminating nationwide dementia initiatives. DDRC's website and social media are the centre's main platforms for dissemination and interacting with users.

NATIONAL DEMENTIA STRATEGY 2025

In 2017 the Danish Ministry of Health launched National Dementia Strategy 2025 and an action plan with 23 initiatives for 2017-2019. Since then, 11 of these initiatives have received further financial support, and DDRC is responsible for conducting the following two initiatives:

- Validation of BASIC in general practitioner clinics. BASIC is a new dementia case-finding instrument.
- Implementation of DemTool (Værktøjskassen) in 15 Danish Municipalities. DemTool is a manualised set of methods and tools for psycho-social support, counselling and education for people with dementia and informal caregivers.
- Testing use of volunteers to patients with dementia in Danish Hospitals. Volunteers with specific training in dementia assists patients with dementia and their carers during hospitalization. The volunteers may provide emotional care, safety and wellbeing for the patients during hospitalization.

COURSES AND CONFERENCES

National Information and Education Centre on Dementia offers a wide range of courses both nationwide and tailored courses and we have annual conferences, e.g. the Dementia Days conference and our research conference. Due to the COVID-19 pandemic most of the course and conference activities had to be cancelled in 2020, but we succeeded in postponing some of the events to 2021.

Course 2020

We had planned 17 courses in 2020, but only a few were carried through, due to the COVID-19 situation. These addressed Young onset dementia and Cognitive Stimulation Therapy. In addition, we delivered seven tailored courses.

Dementia Days – A national conference

Unfortunately, Dementia Days 2020 also had to be cancelled. This annual conference has been held since 1999, and it is Denmark's largest conference on dementia. Every year we convene professionals who work with dementia in a wide range of settings, e.g. staff working in the social or health care services, general practitioners, stakeholder organisations, managing staff and researchers, for a this national two-day conference.

Scandinavian conference for leaders in dementia care

Every other year DDRC is involved in organising a two-day conference for leaders in dementia care in collaboration with Norwegian and Swedish national research and education centres. The theme that was planned for the 2020 conference in Stockholm was "Person-centred culture in dementia care – The responsibility of the manager", but the conference had to be postponed to 2022 due to the pandemic situation.

ABC DEMENTIA – FREE E-LEARNING COURSES

Offering free e-learning is one way of providing easy-access nation-wide education on dementia to various target groups. The e-learning courses are user friendly, e.g. due to the practice-oriented nature of the topics and the varied educational approaches used in the programmes. DDRC has developed five separate e-learning programmes.

ABC Dementia Challenging Behaviour targets care staff in municipalities and it adds to the e-learning course ABC Dementia-Care. It was rereleased in November 2020.

ABC Dementia Care addresses dementia from a broader perspective and targets a wide range of professional care-



One of the education activities offered by DDRC is training professionals to conduct Cognitive Stimulation Therapy (CST). CST is a manualised intervention, where people with dementia are engaged in various activities to stimulate cognition, e.g. group discussions and creative activities.

givers. Each module is designed to cover a specific topic, e.g. dementia diseases, behavioural symptoms or communication. On average, about 800 new users are registered each month.

ABC Dementia for Physicians targets medical doctors under training as e.g. geriatrics, neurologists, psychiatrists or general practitioners, and is also used by other professionals who work with dementia assessments. It was launched in 2016, and around 40 new users register each month.

ABC Dementia for Hospitals targets care staff at hospitals who has basic knowledge about dementia. It was launched in 2018, and it has around 75 new users each month.

ABC Dementia-Friendly Hospitals targets all hospital staff. It is a short programme that gives a general introduction to dementia, including the challenges that are often seen when a person with dementia is admitted to hospital. It also introduces how staff can tailor their communication and care to people with dementia. It has around 125 new users each month.

DDRC'S NATIONAL NETWORKS

To promote exchange of knowledge, education and quality programmes, The National Information and Education Centre on Dementia arrange national networks for various groups of dementia professionals and experts.

Network of Danish Memory Clinics

The Network of Danish Memory Clinics serves as a platform for dissemination and exchange of information, for harmonising and standardising assessment and treatment methods, and for strengthening local and national collaboration on dementia. Members are multi-disciplinary staff such as nurses, medical doctors and neuropsychologists, who mainly work at in hospitals, at psychiatric, geriatric or neurological departments. They receive patients referred from local general practitioners for diagnostic evaluation of dementia. Network members meet once a year to maintain and further develop national cooperation. The network was formed by DDRC in 2008. This year's network meeting was cancelled due to the COVID-19 pandemic. Five research active memory clinics form the "ADEX network" and are partners in Trial Nation Denmark (see research section).

National network of municipality-based dementia ambassadors

Each of the 98 Danish municipalities has appointed a dementia ambassador who participate in this network. The network was formed to disseminate information about DDRC's activities, and to monitor local needs for education activities. The network also forms an important setting for exchanging knowledge and information among local dementia professionals. The network has one annual meeting, and in addition a special newsletters is published six times a year. The 2020 meeting had to be cancelled due to the COVID-19 pandemic.

DaneDem – network for psycho-social research

Danish research network on psychosocial methods in dementia (DaneDem) was formed to promote psychosocial research in dementia in Denmark. The network was inspired by the pan-European network for dementia researchers, Interdem. The aim of the network is to give researchers opportunity to meet and exchange knowledge on various psychosocial methods and research topics, and to promote collaboration and more activity within this field of research. The network has two annual meetings, and due to the pandemic situation, a meeting was converted to an online meeting in 2020.

Network for Dementia-friendly Hospitals

The network serves as a platform for inspiration and exchange of information about dementia-friendly initiatives in Danish Hospitals. The network is an open-access national network for participants with various mainly clinical background, such as nurses, therapists and doctors who work at hospitals. It is required that participants are interested in dementia-friendly initiatives, but no personal experiences are required. Participants meet once a year to establish and maintain partnerships and cooperation across hospitals. Establishment of the network follows the intervention-study of dementia-friendly hospitals from 2017-2019. The first meeting in 2020 was cancelled due to the COVID-19 pandemic.

COMMUNICATIONS AND PRESS – INTERACTING WITH SOCIETY

DDRC in the press

DDRC is present in the media on an almost daily basis with comments, interviews, and articles. In 2020 we had around 540 media references, and about 20 of these were on radio or television. Here experts from DDRC commented on various topics, for instance the how COVID-19 pandemic influences people living with dementia, both with regards to the increased mortality risk and the consequences of isolation and loneliness. Also a documentary on Danish TV2 gave examples of reprehensible conditions in Danish nursing homes, and DDRC contributed with expert perspectives in the debate that followed this documentary.

Website

In 2020 more than 390.000 visited DDRC's website and accessed our subsites 1.3 million times in total. Major themes on our website are e.g. information on the vari-

ous dementia diseases, risk factors, and numbers and statistics. To comply with the need for information on the COVID-19 pandemic and dementia we have also added a subsite dedicated to this topic. Visitors on our website are most often professionals who work with diagnostics, treatment or care. But in addition to professionals, journalists, patients, and informal caregivers also use our website to obtain information on dementia.

Materials and tools, e.g. diagnostic criteria or assessment tools used in clinical practice can also be downloaded from the website or ordered from our web shop.

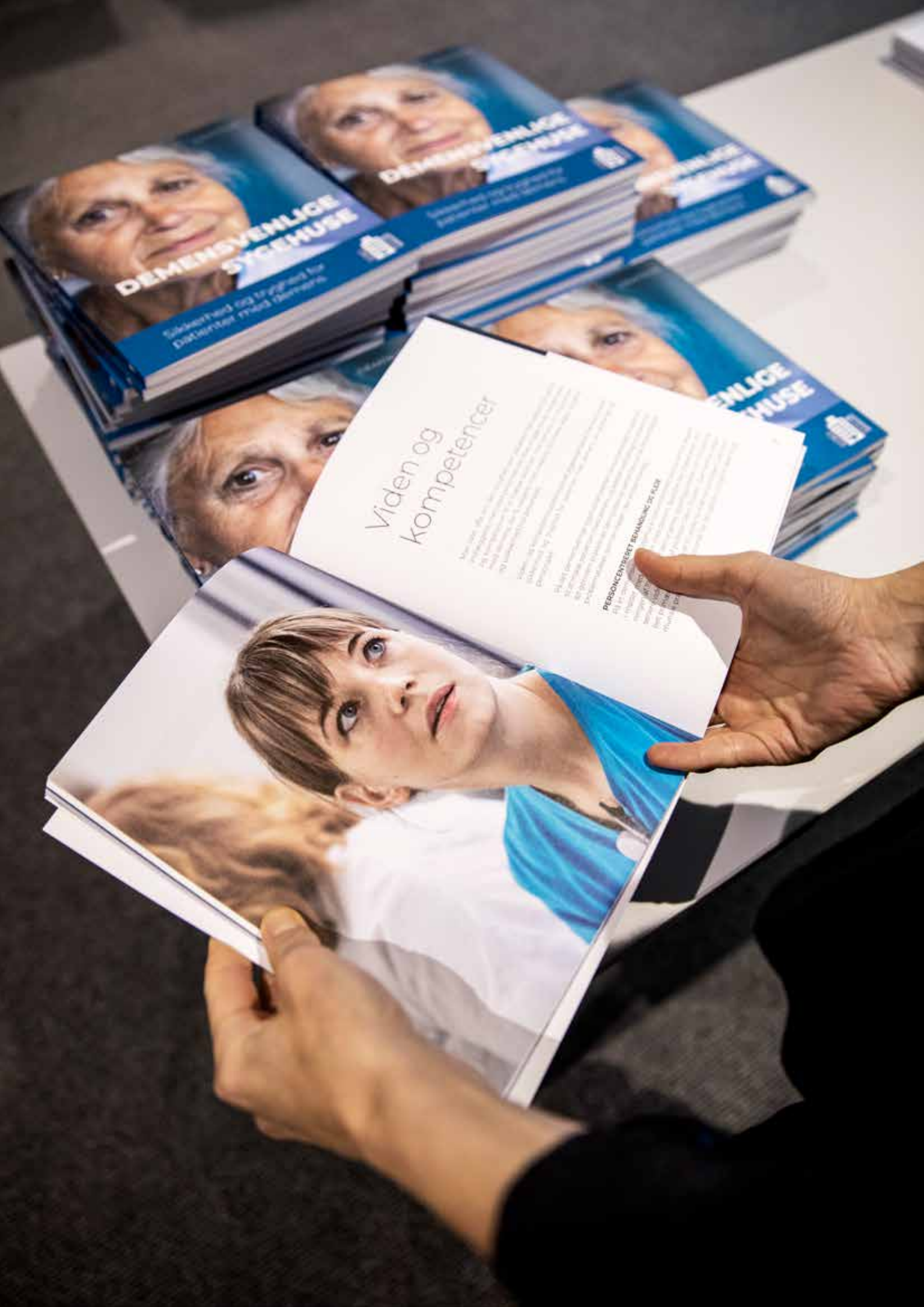
In January 2021 we will launch a new version of our website. New legislation on web accessibility necessitated these changes, and we used the opportunity to develop a new website where the layout now corresponds to DDRC's general line of design. Moreover, all the information on the website was also revised and updated by a group of DDRC web-editors. As part of this, the English subsite (www.ddrc.dk) has also been updated.

Social media

We have had an increasing number of followers on all our social media platforms. This has also engaged more users and generated more traffic on the DDRC website. We find that Facebook is a useful way to connect with the public and to disseminate knowledge about dementia and DDRC's activities, e.g. our activities, courses, and conferences. Twitter is useful to spread news about our research activities and connect with politicians and the media. And we use LinkedIn to share updates with professionals and other stakeholders on various topics related to dementia and DDRC's activities.

Newsletter

The DDRC newsletter was published seven times in 2020. The newsletter presents news from national and international dementia research and provides information on DDRC's activities, e.g. courses and conferences. By the end of 2020 it had 5.500 subscribers. As part of the re-design of our website the newsletter was also updated with new design and new features, and will be launched in January 2021.



Viden og kompetencer

Demens er en af de mest udbredte sygdomme i Danmark. I 2020 blev der diagnosticeret 14.000 nye personer med demens, og i 2025 forventes det, at der vil være 140.000 personer med demens i Danmark. Det betyder, at der er brug for flere kompetente medarbejdere i sundhedssektoren, der kan hjælpe og støtte mennesker med demens og deres pårørende.

Personcentreret behandling er en tilgang til sundhedspleje, der sætter patientens behov og ønsker i centrum. Det betyder, at medarbejderne arbejder sammen med patienten og pårørende for at sikre den bedste mulige behandling og støtte. Personcentreret behandling er en vigtig del af den moderne sundhedspleje, og det kræver, at medarbejderne har de rette kompetencer og viden.

PERSONCENTRERET BEHANDLING OG ROLLE

Personcentreret behandling er en tilgang til sundhedspleje, der sætter patientens behov og ønsker i centrum. Det betyder, at medarbejderne arbejder sammen med patienten og pårørende for at sikre den bedste mulige behandling og støtte. Personcentreret behandling er en vigtig del af den moderne sundhedspleje, og det kræver, at medarbejderne har de rette kompetencer og viden.

NATIONAL AND INTERNATIONAL POSTS

Birgitte Bo Andersen, inspector, Danish Health and Medicines Authority (appointed by the Danish Neurological Society); appointed member, Dementia Council of the Capital Region of Denmark; appointed member (local chair), steering committee for revision of the patient care pathway programme for dementia in the Capital Region of Denmark.

Nadia Falcon Bærnthsen, board member and manager of quarterly meetings and annual assembly, Danish Neuropsychological Society.

Kristian Steen Frederiksen, co-chair, EAN Scientific Panel on Dementia and Cognitive Disorders, member EAN Scientific Panel on Higher Cortical Functions; appointed member EAN Guideline Production Group; chair, EAN Guideline on "Medical management issues in dementia"; representative, Danish Alzheimer Association; board member, Alzheimer Research Committee under the Danish Alzheimer Association.

Steen G. Hasselbalch, board member, Danish Alzheimer Association; board member, Danish Alzheimer Research Foundation, chair, Alzheimer Research Committee under the Danish Alzheimer Association; working group member, National Guideline on diagnosis of MCI and Dementia, Danish Health Authority; member, Scientific Panel on Dementia and Cognitive Disorders, EAN.

Lena Hjermand, Adviser in the European Huntington's Disease Network (EHDN); member of two EHDN working groups "Genetic testing and counselling" and "Symptomatic treatment and research"; board member, European Dystonia Network; appointed member, Tvangsbehandlingsnævnet, the Danish Patient Safety Authority.

Kasper Jørgensen, neuropsychology consultant, Danish Patient Safety Authority; board member, Dansk Psykologisk Forlag.

Jørgen E. Nielsen, Danish national coordinator and PI of the global observational study on HD, Enroll-HD; board member, international SPATAX network on cerebellar ataxias and spastic paraplegias; advisor, European Huntington's Disease Network and steering committee member, EHDN REGISTRY; appointed member, research board, Rigshospitalet; appointed member, European Academy of Neurology, scientific panel in neurogenetics; appointed member, working group for clinical application of WGS, Danish National Genome Center.

T. Rune Nielsen, co-founder and member, Nordic Research Network on Dementia and Ethnicity coordinated by the Nordic Welfare Centre; co-founder and member, European Consortium on Cross-Cultural Neuropsychology; appointed member, Alzheimer Europe expert group on the development of intercultural care and support for people with dementia from minority ethnic

groups; appointed member, International Neuropsychological Society special interest group on Culturally Appropriate Neuropsychological Assessment.

Signe Pertou Ringkøbing, board member and secretary, Danish Neuropsychological Society.

Jette Stokholm, neuropsychology consultant, Danish Patient Safety Authority; neuropsychology consultant, National Legal Medicine Council.

Hanne Sørensen, appointed member, Dementia Council of the Capital Region of Denmark; appointed member, steering committee for revision of patient care pathway programme and education for dementia, Capital Region of Denmark.

Karen Tannebæk, member, Nordic Dementia Network established by Nordic Welfare Centre; member, Danish Network on Psychosocial Methods in Dementia (DaneDem); member, reference group Knowledge Center on dignified elderly care; member, follow-up group on national dementia action plan, Danish Health Authority; member follow-up group on Action plan to prevent and deal with extroverted behavior in elderly care; Danish Health Authority.

Asmus Vogel, section editor, *Scandinavian Journal of Psychology*; member, European research network Brain Involvement in Dystrophinopathies.

Gunhild Waldemar, board member (president-elect), Alliance for Biomedical Research in Europe; member, Executive Committee of the European Alzheimer's Disease Consortium; member, Medical and Scientific Advisory Panel of Alzheimer's Disease International; member, Expert Advisory Panel, Alzheimer Europe; Member, World Federation of Neurology, Standards and Evaluation Committee; member, Board of Trustees and chair, Grants and Prize Committee Lundbeck Foundation; advisor, National Legal Medicine Council, Danish Ministry of Justice; vice-chair, Dementia Council, Capital Region of Denmark; executive committee member, Neurology Council, Capital Region of Denmark; medical lead, Trial Nation Denmark Dementia Centre; chairman, chairman, KFJ clinical research prize committee, University of Copenhagen.

Laila Øksnebjerg, member of the scientific committee of 14th Nordic Meeting in Neuropsychology, Denmark 2021; core member of Nordic Research Network on Health and Welfare Technology; member of InterDem a pan-European network on research and dissemination of psychosocial interventions in dementia and member of Interdem taskforces: Positive Health, Assistive Technology; founder of DaneDem, Danish research network on psychosocial methods in dementia.

STAFF IN 2020

MANAGEMENT GROUP (per 31/12/2020)



Chair
Gunhild Waldemar, MD,
DMSc, professor, senior
neurologist



Head nurse
Copenhagen Memory Clinic
Hanne I. Sørensen, RN



Clinical director
Copenhagen Memory Clinic
Birgitte Bo Andersen, MD,
DMSc, senior neurologist



Research director
Steen G. Hasselbalch,
MD, DMSc, professor,



Research director
Jørgen E. Nielsen, MD,
PhD, professor, senior
neurologist senior
neurologist senior
neurologist



**Director Clinical Trial
Unit (CTU)**
Kristian Steen
Frederiksen, MD, PhD,
senior neurologist



Educational director
Karen Tannebæk,
occupational therapy
specialist



**Director of
communications and
press**
Marie Ejlersen, MA



Centre manager
Troels T. Nielsen,
PhD, MSc



Head of administration
Tine Olsen

EMPLOYED AS OF 31/12 2020

CHAIR

Gunhild Waldemar, MD, DMSc, professor,
senior neurologist

ADMINISTRATION

Jette Gotlieb Iversen, course
administrator
Ditte Majgaard Jensen, accounting staff
Brit Mouritsen, personal assistant
Tine Olsen, head of administration
Jette Marie Rasmussen, research
administrator

NATIONAL PROJECTS, COMMUNICATION AND EDUCATION

Tove-Marie Buk, RN, educational advisor
Marie Ejlersen, MA, director of
communications and press
Thea Emborg, MA, communication
officer
Ulla Vidkjær Fejerskov, OT, educational
advisor
Hanne Kærsmose Friberg, RN,
educational advisor
Elsebeth Glipstrup, RN, educational
advisor
Kasper Jørgensen, MSc,
neuropsychologist
Jette Gerner Kallehauge, OT, educational
advisor, project manager
Mette Højrup Kjær, MA, communications
officer
Ann Nielsen, MScPH, PhD, project
manager
Elsebeth Refsgaard, RN, educational
advisor, project manager
Karen Tannebæk, OT, educational
director
Laila Øksnebjerg, MSc, PhD,
neuropsychologist, project manager

RESEARCH

Andreas Appel, MScPH, PhD student
Anna E. Bruus, MSc., neuropsychologist,
PhD student
Patrick Ejlerskov, MSc, PhD, post.doc.
Kristian Steen Frederiksen, MD, PhD,
senior neurologist, senior researcher,
CTU director
Julia Gusatovic, student researcher
Steen Gregers Hasselbalch, MD, DMSc,
professor, senior neurologist
Marie Nickelsen Hellum, MD, PhD
student
Rebecca Hendel, MSc,
neuropsychologist, PhD student
Emil Elbæk Henriksen, MSc, PhD student
Lena Elisabeth Hjermand, MD, PhD,
senior neurologist, senior researcher
Janet Janbek, MScPH, PhD student
Camilla Steen Jensen, MSc, PhD, post.doc.

Kasper Jørgensen, MSc,
neuropsychologist, senior researcher
Adele Gabriele Marthaler, PhD, post.doc.
Christian Sandøe Musaeus, MD, PhD
student
Jørgen Erik Nielsen, MD, PhD, professor,
senior neurologist
T. Rune Nielsen, MSc, PhD,
neuropsychologist, post.doc.
Troels Tolstrup Nielsen, MSc, PhD, centre
manager
Peter Roos, MD, PhD, neurologist, senior
researcher
Anja Hviid Simonsen, MSc, PhD, senior
researcher
Camilla Steen-Jensen, MSc, PhD, post.doc.
Anders Toft, MD, PhD student
Asmus Vogel, MSc, PhD,
neuropsychologist, associate professor
Laila Øksnebjerg, MSc, PhD,
neuropsychologist, senior researcher

COPENHAGEN MEMORY CLINIC

Medical doctors

Birgitte Bo Andersen, MD, DMSc, senior
neurologist, clinical director
Eva Bjerregaard, MD, specialist in family
medicine
Line Damsgaard, MD
Kristian Steen Frederiksen, MD, PhD,
senior neurologist
Hanne Vibe Hansen, MD, senior
psychiatrist
Steen Gregers Hasselbalch, MD, DMSc,
professor, senior neurologist
Lena Elisabeth Hjermand, MD, PhD,
senior neurologist
Tina Kolenda, MD (maternity leave)
Suzanne Lindquist, MD, PhD, associate
professor, clinical geneticist
Jørgen Erik Nielsen, MD, PhD, professor,
senior neurologist
Nelsan Pourhadi, MD
Peter Roos, MD, PhD, neurologist
Christina Rørvig-Løppenthien, MD,
senior neurologist
Lise Cronberg Salem, MD, PhD,
neurologist
Sarah Taudorf, MD, PhD, senior
neurologist
Tua Vinther-Jensen, MD, PhD,
neurologist
Fia Vosborg, MD

Nurses

Nicole Cordes, RN
Lea Virenfeldt Damgaard, RN
Birgit Grøn, RN
Christina Vangsted Hansen, RN,
research nurse

Lene Iben Hvidkjær, RN
Oda Jakobsen, RN, research nurse
Mette Janerka, RN
Rikke Charite Monberg Jarløv, RN
Hanne Rygaard Jensen, RN
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Mette Nyboe, RN
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RESEARCH ARTICLE

WILEY



Validation of the Brief Assessment of Impaired Cognition and the Brief Assessment of Impaired Cognition Questionnaire for identification of mild cognitive impairment in a memory clinic setting

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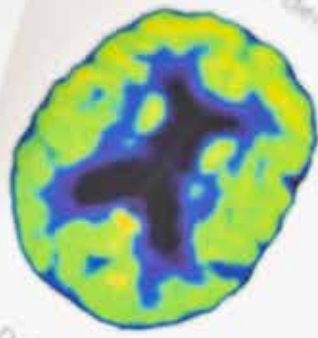
Objectives: The aim of this study was to validate the Brief Assessment of Impaired Cognition (BASIC) and the Brief Assessment of Impaired Cognition Questionnaire (BASIC-Q) for identification of mild cognitive impairment (MCI) in a memory clinic setting.

Methods: A total of 143 sociodemographically matched patients (MCI), $n = 42$, and 101 controls ($n = 121$) and 83 control participants were included in the study. Two instruments were validated: (i) BASIC, including the components self-report, informant report, and two brief cognitive tests, and (ii) BASIC-Q including the components self-report, informant report, and informant report. BASIC can be administered in 5 minutes and BASIC-Q in less than 5 minutes.

Results: A high discriminative validity for MCI in control participants was found for both BASIC (sensitivity 0.86) and BASIC-Q (sensitivity 0.82) and moderate specificity (0.70). In comparison, the MMSE had the sensitivity 0.82 and moderate specificity (0.68). All components of BASIC and BASIC-Q contributed significantly to the identification of MCI from control participants. The components of BASIC and BASIC-Q report, which was identical in the informant MCI from dementia, except for self-report, which was identical in the informant MCI from dementia, except for self-report.

Conclusion: Both BASIC and BASIC-Q are brief, valid, and effective instruments for identification of patients with possible MCI in a memory clinic setting. Further validation of the instruments in a general practice or primary care setting is needed.

KEYWORDS:
BASIC, BASIC-Q, dementia, memory clinic, mild cognitive impairment, validation



PhD thesis
Le Gjerum

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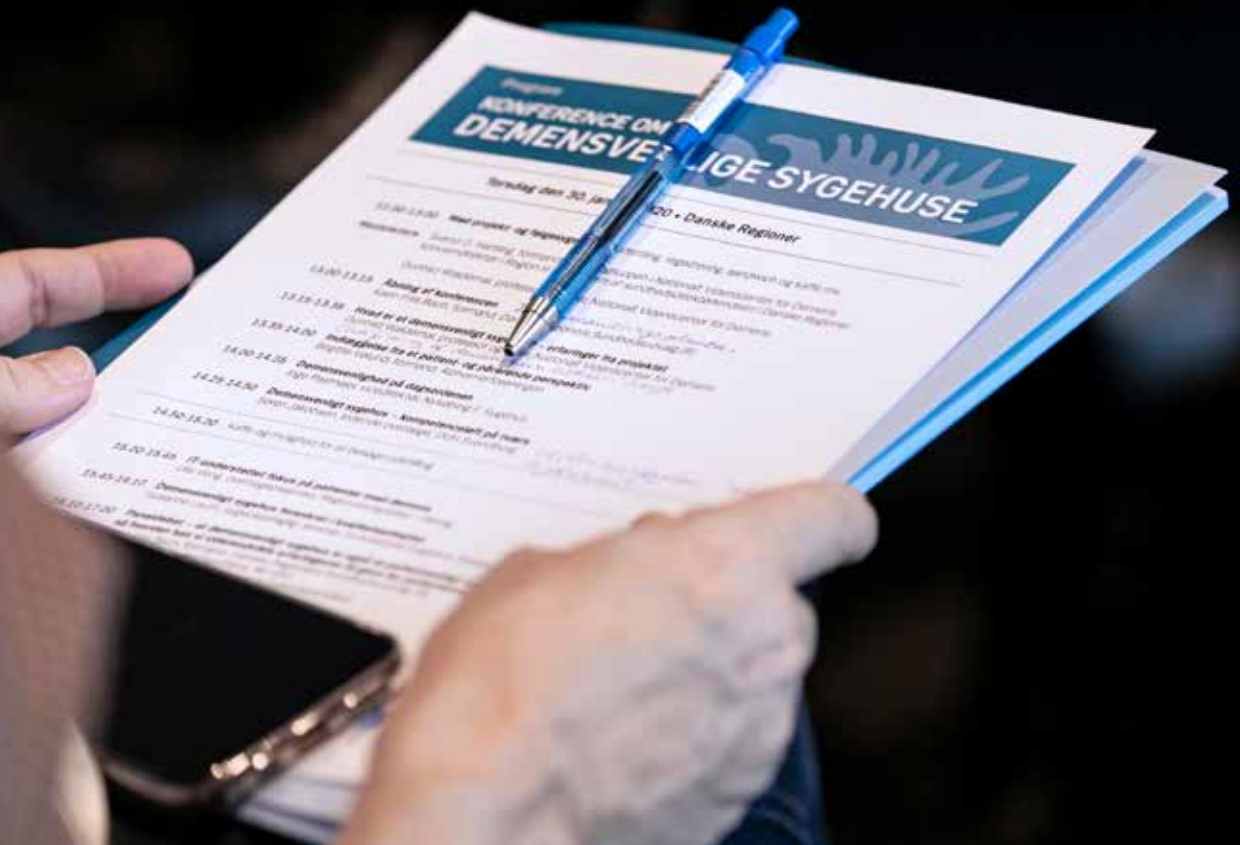
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Professionals at DDRC are highly committed to disseminate knowledge achieved in interventions and research projects.



FINANCING

The DDRC's total annual budget for 2020 was approximately DKK 62.2 m, distributed almost evenly between internal funding (DKK 29.9 m for memory clinic services) and external grants (DKK 32.3 m for research, contracts and

educational activities). In 2017 the grant to National Information and Education Centre for Dementia from the Danish Ministry of Health was made permanent.

EXTERNAL FUNDING FOR RESEARCH, QUALITY PROJECTS AND EDUCATION ACTIVITIES 2020 (DKK M)	
New grants received*	18.2
New grants accumulated 2007-2020*	226.6
External grants spent on specific programmes and projects	27.0
• National Information and Education Centre for Dementia from the Danish Ministry of Health, including projects	13.4
• Other external grants for research*	6.5
• Grant to Danish Memory Clinics**	7.1
Conferences, educational courses and products	0.8
Research contracts	4.5

* excluding the annual main grant from the Danish Ministry of Health

** grant from the Danish Ministry of Health for the development of multidisciplinary memory clinics according to the new recommendations from the Danish Health Authority. A National Dementia Plan initiative

STAFF 2020	
No. of employees/full-time equivalents	91/79

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