Evaluation of Medicine and Health (EVALMEDHELSE) 2023-2024

Self-assessment for research groups

Date of dispatch: **15. September 2023** Deadline for submission: **31. January 2024**

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1. Organisation and strategy

1.1 Research group's organisation

Describe the establishment and the development of the research group, including its leadership (e.g. centralised or distributed etc.), researcher roles (e.g. technical staff, PhD, post docs, junior positions, senior positions or other researcher positions), the group's role in researcher training, mobility and how research is organised (e.g. core funding organisation versus project based organisation etc.).

Research on Parkinson's disease at Stavanger University Hospital began in the 1990s, driven by clinical neurologists specialising in movement disorders. The initial research focused on studying the prevalence and evolution of Parkinson's disease in Norway using a population-based clinical-epidemiological approach and garnered national and international acclaim.

In 2003, Stavanger University Hospital was assigned The National Advisory Unit on Movement Disorders, with the national responsibility to generate and spread knowledge on movement disorders to health care providers, patients, and decision-makers. The National Advisory Unit came into operation in 2004 and a research group on Movement Disorders (named "The Norwegian Centre for Movement Disorders") was formally established the same year.

Around the same time, the research group initiated the Norwegian ParkWest study, a large populationbased clinical-biological long-term research project with the aim to study the incidence, neurobiology, and prognosis of Parkinson's disease. This study significantly expanded the research scope and activities, and the group became more interdisciplinary, now including a broader range of clinical researchers (neurologists, psychologists, radiologists, nurses). From 2012, the group increasingly focused on biomedical research and evolved into a highly interdisciplinary group incorporating a growing number of basic scientists, establishing and expanding its own lab facilities, and fostering collaborations across Scandinavia, Europe and the US.

Since 2016, the National Advisory Unit has been responsible for establishing and running the Norwegian Parkinson Registry and Biobank, a national medical quality registry and a potential source for future population-based clinical and biomedical research. Following the establishment of the National Parkinson Registry, the research group started to develop a "smart and decentralized" research infrastructure to allow for remote biosampling and follow-up of participants regardless of where they live in Norway. This approach is still under development but is already used by the group in a growing number of projects, including studies of prodromal Parkinson's disease and clinical trials.

In 2020, following a successful pilot project, the National Advisory Unit was assigned the responsibility to coordinate the national implementation of ParkinsonNet, aiming to build interdisciplinary healthcare networks across Norway for optimal treatment and quality of life of people with Parkinson's disease.

In promoting a dynamic research environment, the group facilitates mobility by supporting visits to collaborating labs in academia and industry. We have contributed to international educational exchange programs and the researchers' prolific attendance at congresses and meetings reflects a commitment to continuous learning, global networking, and knowledge dissemination.

The research group is a subunit of the National Advisory Unit under the Department of Research at Stavanger University Hospital. The research group has centralised leadership and comprises positions dedicated to research (2 senior researchers, 1 statistician, 7 project-based PhD/postdocs, 2 study nurses) and 6 physicians/psychologists with dual roles in research and clinics. Complementing these are 2 administrative members. The group offers researcher education from BSc to postdoc levels and contributes to the clinical training and education of neurologists and other health care professionals.

The group's permanent research positions are funded by the Norwegian Ministry of Health and Care Services and Stavanger University Hospital. Remaining activities and positions are secured by projectbased funding from multiple national and international sources (for details see 1.4 "Research group's resources").

Table 1. List of number of personnel by categories

Instructions: Please provide number of your personnel by categories. For institutions in the higher education sector, please use the categories used in DBH, <u>https://dbh.hkdir.no/datainnhold/kodeverk/stillingskoder</u>.

	Position by category	No. of researcher per category	Share of women per category (%)	No. of researchers who are part of multiple (other) research groups at the admin unit	No. of temporary positions
No. of	Senior physicians	4	50	0	0
Personnel	Physicians	1	0	0	0
by	Psychologists	1	0	1	0
position	Researchers and postdocs	6	67	1	4
	PhD-students	4	100	0	4
	Research support/	4	100	0	1
	Administrative research staff				

1.2 Research group's strategy

a) Describe the research group's main goals, objectives and strategies to obtain these (e.g. funding, plans for recruitment, internationalization etc.) within the period 2012-2022.

The research group's main goal is to conduct internationally leading clinical and biomarker research to improve diagnostics, treatment, and care of people with Parkinson's disease and related disorders. To achieve this goal, our strategy has been guided by four specific objectives during the period 2012-2022:

- 1. "Building the content": We have focused on collecting "unparalleled" clinical and biological data through research initiatives such as the ParkWest study, the Prodromal Lewy Body Disease study, and the National Parkinson Registry and Biobank, with funding secured from multiple sources.
- 2. "Building the team": We prioritised the recruitment of an interdisciplinary team including basic scientists with relevant expertise. Core funding was secured for permanent senior positions, followed by project-based funding for PhD and postdoc positions.
- 3. **"Building the infrastructure**": An essential aspect of our strategy involved building and extending own lab facilities, including the acquisition of relevant state-of-the-art lab equipment. Funding for these initiatives was obtained from multiple sources.
- "Building collaborations": We actively fostered collaborations with national and international partners to a) exchange knowledge and enhance skills; b) optimize the use of own data and others';
 c) stimulate researcher mobility; d) increase research output, and e) diversify funding opportunities.

Following the establishment of the Norwegian Parkinson Registry and Biobank, an additional objective was added in 2017:

5. **"Making research accessible**": Our commitment extends to making research accessible to patients by developing a smart and decentralized research infrastructure. This includes successfully implementing homebased biosampling and ongoing efforts in clinical follow-up.

These strategies collectively form a comprehensive roadmap that aligns with our overarching goal of advancing clinical and biomarker research in Parkinson's disease and related disorders.

b) Please describe the benchmark of the research group. The benchmark for the research group should be written by the administrative unit in collaboration with the research group. The

benchmark can be a reference to an academic level of performance (national or international) or to the group's contributions to other institutional or sectoral purposes.

Example: A benchmark for a research group is related to the research groups' aim which again is included in the strategy for the administrative unit. A guidance for the administrative unit to set a benchmark for the research group(s) can e.g. be: What do the administrative unit expect from the research group(s)?

The administrative unit expects the research group to conduct international recognised research on Parkinson disease and related disorders. Key benchmarks for success in the period 2012-2022 are:

Research Group and Resources

- 1. Offer at least 5 PhD/postdocs positions at any one time and to increase this over time.
- 2. Strengthen existing collaborations and establish new partnerships to optimize the utilization of data and resources and to diversify the research portfolio.

Scientific

- 3. Publish a minimum of 15 paper annually, with a focus on increasing the share in highly relevant journals for our field or that meet the unit's criteria for quality.
- 4. Increase the number of projects managed by the group and be involved in at least one clinical trial and one innovation project at any one time.

Education

5. Actively contribute to education at all levels, presenting at a minimum of two international conferences and participating in higher education sector programs or initiatives.

Economic

- 6. Increase overall research funding from national and international sources by 50% over a five-year period.
- 7. Participate in at least one NFR and one EU project at any one time.

User involvement

8. Foster active collaboration with users, defined as patients and next of kin, in all phases of the research, with biannual face-to-face meetings and running dialogue on active research projects.

c) Describe the research group's contribution to education (master's degree and/or PhD).

Both clinical and scientific education are integral parts of the group's daily activities. Group members routinely organize and contribute to basic and specialized clinical training and education for neurologists, psychologists and other health care professionals. Scientific training and education is provided from BSc to postdoc levels, encompassing different fields and disciplines such as clinical and basic neuroscience, neurology, psychiatry, psychology, biomedicine, biological chemistry, pathology, nursing, physiotherapy, occupational therapy and clinical nutrition.

Several group members hold formal academic affiliations with the University of Stavanger (1 professor, 4 associate professors) or the University of Bergen (1 associate professor), and actively participate in the development and delivery of graduate programs and courses. Additionally, one group member held a visiting professorship at King's College London, UK, from 2018 to 2021.

The research group's contributions to BSc, MSc, PhD, and postdoc education between 2012 and 2022 is summarised below. Students were registered at the University of Stavanger, University of Bergen, University of Oslo, Oslo Metropolitan University, and University of Copenhagen.

	BSc	MSc	PhD	Postdoc	Overall
Completed	10	11	11	7	39
Ongoing	0	1	5	2	8
Total	10	12	16	9	47

d) Describe the support the host institution provides to the research group (i.e., research infrastructure, access to databases, administrative support etc.).

Our research group benefits from a range of support services provided by the administrative unit, which are essential to our ability to conduct high-quality research. The support includes:

- 1. **Biostatistical Resources**: Assistance in building and maintaining databases of high quality, statistical analysis and guidance, and biostatistical education.
- 2. **Clinical Research Unit**: Provision of infrastructure for collecting, processing and storage and biological samples.
- 3. **Biobanking Services**: Provision of infrastructure and support for biobanking of samples from the group's research project.
- 4. **Grant Application Support**: Support and guidance in the application process for external funding (both national and international) and subsequent management of projects.
- 5. **Training in Good clinical practise (GCP)**: Access to mandatory training in GCP to ensure ethical and quality clinical research practices.
- 6. **Legal Guidance**: Judicial guidance in preparing and negotiating legal agreements for research collaborations and data sharing.
- 7. Access to National Network: Access to the national network for researchers (Norwegian Clinical Research Infrastructure Network; NORCRIN) facilitating collaborations and resource sharing at the national level.

1.3 Relevance to the institutions

Describe the role of the research group within the administrative unit. Consider the research group's contribution towards the institutional strategies and objectives, and relate the research group's benchmark to these.

The research group is part of the National Advisory Unit on Movement Disorders. This unit is the only National Advisory Unit (out of a total of ~50 nationwide) to be located at Stavanger University Hospital. Further, the group hosts the National Parkinson Registry and Biobank, one of only three national medical quality registries at Stavanger University Hospital, underlining our **central role in nationwide healthcare initiatives.**

The research group aligns its research with the mandate of the advisory unit, the Research and Innovation Strategy of the Western Norway Regional Health Authority, and the Research Strategy of Helse Stavanger. This ensures that our research is directly relevant to the hospital's overarching goals, including patient treatment and education, research, and training of healthcare personnel. Further, our research strategy is guided by our commitment to contribute to the benchmarks set by the administrative unit in key areas:

The Research Group and Resources

- Through proactive efforts in seeking funding opportunities, we have successfully increased the number of project-based PhD/postdoc positions to 7 by 2022, contributing to the administrative unit's goal to increase the number of PhD/postdoc positions.
- We have actively cultivated collaborations and extended partnerships in diverse fields. The success of this strategy is underlined by the fact that >90% of our research publications from 2018-2022 include an external co-author from within Norway or abroad.
- We have secured funding to bring state of the art equipment to Stavanger University Hospital and have made this available to other research groups, both locally and internationally.

Scientific

- We have produced 74 publications (2018-2022), with 25% of these in level 2 journals, aligning with our administrative unit's targeted expectation for journal quality.
- We have expanded the number of projects managed by the group and are currently involved in 2 innovation projects and 2 clinical trials, exceeding our benchmark.
- We have contributed to the administrative unit's goal to increase research-based innovation by developing a new test for the early molecular diagnosis of Parkinson disease, successfully filing for a patent in 2022.

Education

- We actively contribute to all levels of education, spanning clinical and university settings. Our involvement includes the supervision of research projects from BsC to postdoc level (total of 47 projects; see section 1.2c).
- In line with the unit's expectations, the number of employees with professor competence has increased by one, accompanied by 3 new associate professors.

Economic

- By increasing efforts, diversifying our research portfolio, and engaging with new funding bodies, we have increased our external funding by >50% from 2018 to 2022, exceeding our benchmark of a 50% increase over five years.
- Since 2019 we have been involved in one NFR project. While we were actively involved in one EU project until 2020, we are not currently active in this area.
- In line with the administrative unit's goal, since 2019 our external funding from national and international sources has exceeded that from the Western Norway Regional Health Authority.

User Involvement

• We have maintained active engagement with the Norwegian Parkinson Association and secured their direct involvement in new patient centred research projects.

1.4 Research group's resources

Describe the funding portfolio of the research group for the last five years (2018-2022).

The research group's activities are funded by three main sources:

- 1. Basic funding of the National Advisory Unit on Movement Disorders by the Norwegian Department of Health. Approximately 30% of this funding is allocated to research-related activities.
- 2. Basic funding of permanent research positions (including technical/administrative staff) by Stavanger University Hospital.
- 3. Project-based external funding from the private and public sector.

Between 2018 and 2022, the total funding per year increased from 13.8 million NOK to 21.1 million NOK, primarily attributed to a >50% rise in external funding during this period. External funding was obtained from the following sources:

- National, private sector: The Norwegian Health Association, Norwegian Parkinson Research Association, and Reberg's legacy
- National, public sector: The University of Stavanger, Western Norway Health Authority research grants, and The Research Council of Norway
- International, private sector: Reta Lila Weston Trust (UK)
- International, public sector: EU (IMI 2 program)

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	2018 (NOK)	2019 (NOK)	2020 (NOK)	2021 (NOK)	2022 (NOK)
Basic funding	4.500.000	4.650.000	4.800.000	5.000.000	5.150.000
Funding from industry and					
other private sector sources	790.000	2.236.000	2.482.463	1.904.100	2.261.000
Commissioned research for					
public sector	-	-	-	-	-
Research Council of Norway	-	240.000	2.475.000	2.543.200	2.837.400
Grant funding from other					
national					
sources	5.983.500	3.048.500	2.856.165	3.237.026	4.830.095
International funding e.g.					
NIH, NSF, EU framework					
programmes	-	132.500	288.800	299.926	556.777
Other*	2.515.000	2.531.000	3.400.000	5.400.000	5.470.000

Table 2. Describe the sources of R&D funding for the research group in the period 2018-2022.

*Norwegian Parkinson Registry and Biobank, ParkinsonNet Norway

1.5 Research group's infrastructures

Research infrastructures are facilities that provide resources and services for the research communities to conduct research and foster innovation in their fields. <u>These</u> include major equipment or sets of instruments, knowledge-related facilities such as collections, archives or scientific data infrastructures, computing systems communication networks. Include both internal and external infrastructures.

a) Describe which national infrastructures the research group manages or co-manages.

The research group is part of the National Advisory Unit on Movement Disorders, a service established at Stavanger University Hospital by the Norwegian Directorate of Health in 2003. The main purpose of the National Advisory Unit is to generate (e.g. through research) and spread knowledge and expertise to health care providers, patients and decision-makers in order to ensure optimal treatment and equal access to health care services throughout Norway.

The National Advisory Unit manages critical national research infrastructures, including:

- The <u>Norwegian Parkinson Registry and Biobank</u> gained national status in 2016 and commenced data collection in 2019. With a focus on neurodegenerative parkinsonian disorders, encompassing Parkinson's disease and atypical parkinsonism, the registry aims to ensure uniform diagnosis, treatment, and follow-up for these patients. Its contribution extends beyond clinical care, actively supporting research initiatives aimed at a deeper understanding of these disease groups.
- <u>ParkinsonNet</u> is a nationwide healthcare network, prioritizing optimal treatment and enhancing the quality of life for individuals with Parkinson's disease and parkinsonism. The network systematically conducts specialist and interdisciplinary practice-based training for healthcare professionals, comprising occupational therapists, physiotherapists, speech therapists, and nurses, from both the specialist health service, the municipal health service and the private sector. These activities put ParkinsonNet in a unique position to provide a vital resource for much needed research on health care provision in Norway.
- b) Describe the most important research infrastructures used by the research group.

The research group actively utilises a range of research infrastructure:

Equipment/facilities:

- Internal technical infrastructure, including neurophysiology facilities (EEG and PSG) and precision biomarker equipment (e.g. SIMOA technology), established and managed by the research group
- Local infrastructure at Stavanger University Hospital
 - o Clinical Research Unit for collection and handling of biological samples
 - o Biobank facilities and infrastructure
- Local collaborative lab facilities at Stavanger University Hospital and the University of Stavanger
- International collaborative lab facilities and competence, with recent prominent examples including the University of Exeter (UK; epigenetics), The University of Gothenburg (Sweden, proteomics) and Harvard Medical School and the NIA (USA; genetics)

Platforms and networks for data processing:

- Services for sensitive data (TSD), provided by the University of Oslo
- NorCRIN, a partnership between all six university hospitals in Norway
- REDCap, a web application for building and managing online surveys and databases

1.6 Research group's cooperations

Table 3. Reflect on the current interactions of the research group with other disciplines, non-academic stakeholders and the potential importance of these for the research (e.g. informing research questions, access to competence, data and infrastructure, broadening the perspectives, short/long-term relations).

Interdisciplinary (within and beyond the group)	Interdisciplinary cooperation is essential in achieving our benchmark of establishing a robust and international leading research environment. Our group's core strength lies in its interdisciplinary structure, spanning both clinical and basic sciences as previously described, and broad cooperations, as detailed in the sections below. Collaborations extending beyond the group are equally important. We engage with experts in diverse fields such as imaging, pathology, neurophysiology and ophthalmology, fostering positive synergy. Our roots in the clinic, coupled with ongoing collaborations, enhance our ability to establish and develop these interdisciplinary partnerships. In managing extensive research datasets, collaboration with biostatisticians is crucial. During the evaluation period, our group utilised both a dedicated statistician and collaborated with biostatisticians from the administrative unit.
Collaboration with other research sectors e.g. higher education, research institutes, health trusts and industry.	We cooperate with the University of Stavanger, where we've established a lab on campus, enhancing interactions with university staff and students. Additionally, we partner with the University of Stavanger and the University of Bergen for MsC and PhD student research projects. Further, our diverse international collaborations with universities and research institutes have significantly enriched our research, evidenced by >60% of papers featuring co-authors from other countries. In the industrial sector, we have successfully partnered with a biotechnology innovation company, NordicDx (Norway, 2022-present), to commercialize our work, specifically developing an innovative biomarker method into kit-format. Our collaboration with global research foundations, such as the Michael J. Fox Foundation (MJFF) for Parkinson's research, have been instrumental. MJFF have provided funding and also support our work to contribute a substantial amount of data from our projects to a global genetics program, amplifying our potential impact within PD genetics.
Transdisciplinary (including non academic stakeholders) Transdisciplinary research involves the integration of knowledge from different science disciplines and (non- academic) stakeholder communities with the aim to help address complex societal challenges.	Recognising the complexity of challenges in Parkinson's disease, we've proactively sought out new collaborations beyond our field. Since 2017 we have implemented ParkinsonNet in Norway. ParkinsonNet was initiated by the Norwegian government, in collaboration with public health authorities, the user organisation and our group, to transform the way that people with Parkinsonism are cared for. In the industrial sector, recent examples include ongoing clinical trials with a live bacteria supplements manufacturer (Protexin, UK, 2020-present) and integration of innovative home-monitoring technologies as part of our "digital solutions" initiative with a tech company (Vital Things, Norway, 2022-present). Our collaboration with the regional Technology Transfer Office (Valide) has been pivotal in bringing basic research into practical applications, facilitating commercialization projects and patent filings. Legal collaborations worldwide have enabled us to share data globally, helping us to contribute to the communities' efforts to address common societal challenges in both PD and dementia. Finally, one of our most valuable long-term relationships is with the national user organisation, the Norwegian Parkinson Association, who enable patient involvement at all stage of research. The Norwegian Parkinson Association have funded our work and directly guided our research questions through interactions with patients. They have also actively supported our research through marketing, crucial for accessing our target groups.

2. Research quality

2.1 Research group's scientific quality

Describe the research profile of the research group and the activities that contribute to the research group's scientific quality. Consider how the research group's work contributes to the wider research within the research group's field nationally and internationally.

<u>Profile:</u> The research group is a dynamic and interdisciplinary team committed to leading research in Parkinson's disease and related disorders. With a strategic and sustainable approach to research, education, and collaboration, the group actively contributes to advancements in scientific knowledge, positioning itself as a driving force in the field of neurodegenerative research.

Activities that contribute to the research group's quality:

- 1. Longitudinal Observational Studies: We have a longstanding and strong record in conducting highquality observational long-term studies with population-based design and clinically and biologically well-characterized cohorts.
- 2. Interdisciplinary Composition: The group comprises highly skilled personal from a number of disciplines ranging "from bench to bedside".
- 3. **Cutting-edge Biomarker Research**: We have built up extensive experience and established state-of-the-art lab facilities for biomarker research.
- 4. **National Advisory Unit Collaboration**: As part of a larger interdisciplinary team at the National Advisory Unit on Movement disorders, we benefit from daily interactions with clinicians and other colleagues with expertise in related and overlapping fields relevant for our research activities.
- 5. **Strong Collaborations**: We have extensive collaborations, with strong partners nationally and internationally.
- Patient Organisation Engagement: We have close collaborations with patient organisations and user representatives that provide input and feedback to our work and also contribute by both marketing our projects and disseminating our results to users and the public.

We consider the following key contributions of our group to the wider research within the field:

- Advancements in Parkinson's disease knowledge: Our projects and publications (see tables 4 and 5) have enhanced the understanding of Parkinson's disease, with a focus on medical and healthcare practices.
- 2. Innovations in Detection and Prediction: Our work has led to innovations in methods and technologies for earlier and more precise disease detection and prediction of Parkinson's disease and related disorders (see table 4, projects 1-3, 5, 6, 8; table 5, publications 1, 4, 8-10).
- 3. **Knowledge sharing**: We actively share knowledge, expertise, and ideas through collaborations with national and international partners (see table 4, projects 1, 3-6, 8, 9; table 5, publications 4, 5, 6, 8-10), representation in professional associations and contributions to the peer review process in scientific journals.
- 4. Resource and Data Sharing: Our group contributes significantly by sharing expertise, resources, data, and biosamples with collaborators (see table 4, projects 1, 3-5, 8,9; table 5, publications 1, 4-6, 8-10). This collaborative approach accelerates research, reduces costs, and more effectively addresses complex research questions and common societal problems. Additionally, we provide services such as running biomarker analyses at out lab.

Please add a link to the research group's website:

The Norwegian Centre for Movement Disorders - Helse Stavanger HF (helse-stavanger.no)

Table 4. List of projects

Instructions: Please select 5-10 projects you consider to be representative/the best of the work in the period 1 January 2012 – 31 December 2022. The list may include projects lead by other institutions nationally or internationally. <u>Please delete tables that are not used</u>.

Project 1:	Project owner(s) (project	Stavanger University Hospital, Haukeland University Hospital
	leaders organisation)	
The Norwegian PARKVEST	Total budget and share	Annual running costs are ~1.0 million NOK. The group has received multiple fundings for
study	allocated to research group	basic running costs from external sources amounting to ~ 10 million NOK in total from
		2012-2022. Share allocated to the research group: close to 100%.
2004-2034	Objectives and outcomes	Objectives: To determine the incidence, prognosis and neurobiology of Parkinson's disease
	(planned or actual) and link	Outcomes: The ParkWest study has significantly advanced the field's understanding of
	to website	Parkinson disease, resulting in over 100 articles in leading medical journals, with >35% in
		levels 2 journals and >10 editorials, and supporting >15 doctoral theses. This has been
		achieved with collaborators in >20 countries and the results of the study have contributed
		to the design of several clinical trials and patents. The project has not only elevated our
		international standing, but has catalysed numerous new projects, collaborations, and
		funding opportunities. Beyond academia, the project has had a profound impact on many
		levels, leading to changes in clinical practice and reshaping the perception of key Parkinson
		symptoms.
		Link to website: The Norwegian ParkWest study - Helse Stavanger HF (helse-stavanger.no)
Project 2:	Project owner(s) (project	Stavanger University Hospital
	leaders organisation)	
Identification and	Total budget and share	106.000 USD, 100% allocated to research group
Validation of Cerebrospinal	allocated to research group	
Fluid Markers Related to	Objectives and outcomes	Objectives: To identify CSF amyloid-beta processing, tau, microglia activation, synaptic
Altered Amyloid-beta	(planned or actual) and link	function biomarkers for dementia
Processing in the Prediction	to website	Outcomes: This project arose from ParkWest (project 1) findings on dementia biomarkers
of Dementia Associated		in Parkinson disease. Funded by the Michael J. Fox Foundation, we measured a panel of
with Parkinson's Disease		protein biomarkers that had been directly or indirectly linked to altered amyloid-beta
		processing and analysed the link to dementia development using ParkWest clinical data
2014-2015		collected over five years. Amyloid-beta emerged as the most crucial indicator of dementia
		development. Future plans include a reanalysis after ten years. The project supported one
		PhD.
		Link to website: Identification and Validation of Cerebrospinal Fluid Markers

Project 3:	Project owner(s) (project leaders organisation)	Stavanger University Hospital
Biomarkers to predict individual risk of dementia in Parkinson's disease	Total budget and share allocated to research group	8.889.000 NOK; 100% allocated to research group
(ParkDem) 2019-2024	Objectives and outcomes (planned or actual) and link to website	Objectives: To develop a broad biomarker panel that can help physicians identify Parkinson's disease patients at high risk of developing dementia in the future. Outcomes: In ParkDem, we harmonised clinical and biological data from international population-based cohorts to identify key genetic and protein biomarkers of dementia (e.g. paper 9 and 10; Table 4). The work also led to the development of innovative assays, such as the alpha-synuclein aggregation assay and GCase activity assay, laying the foundations for projects 6 and 5, respectively. ParkDem was also the catalyst for new collaborative opportunities, exemplified by our work in paper 5 (Table 4) and a planned collaboration with the Global Parkinson Genetics Program (gp2.org). As of 2022, ParkDem has contributed to 23 publications and presentations at congresses, along with one patent. Link to website: ParkDem-project - Helse Stavanger HE (helse-stavanger.no)
Project 4:	Project owner(s) (project leaders organisation)	Stavanger University Hospital and University of Aberdeen
Parkinson's Incidence Cohorts Collaboration	Total budget and share allocated to research group	Groups have independent funding and contributions from researchers is based on in kind contributions.
2019-t.d.	Objectives and outcomes (planned or actual) and link to website	 Objectives: To establish a dataset of population-based Parkinson studies to improve the analysis of Parkinson's disease. Outcomes: PICC is an ambitious international collaboration, uniting all population-based Parkinson incidence cohorts to elevate the quality and impact of research. Since 2019 we have harmonized data from 6 cohorts, which began recruitment in 2000 and have maintained a continuous follow-up of disease progression. This data has been leveraged by basic and clinical researchers in Norway, Sweden, and the UK, resulting in 5 papers (including Paper 9, see Table 4), presentations at 5 conferences, and contributing to the work of 5 PhD candidates in Norway and abroad. The PICC project has significantly expanded our network, fostering increased international collaboration, with eight ongoing projects with more in the planning stages. Link to website: https://www.abdn.ac.uk/iahs/research/chronic-disease/picc-2071.php

Project 5:	Project owner(s) (project	Stavanger University Hospital and The University of Stavanger
	leaders organisation)	
GCase-Responders Across	Total budget and share	2.940.000 NOK; 100% allocated to research group
Neurodegenerative	allocated to research group	
Diseases (the GRAND	Objectives and outcomes	Objectives: The GCase-Responders Across Neurodegenerative Diseases (GRAND) project
project)	(planned or actual) and link	seeks to improve clinical trials in Parkinson and related diseases.
	to website	Outcomes: GRAND builds upon ParkDem (project 3) to expand our findings on dementia in
2020-2024		Parkinson disease to Dementia with Lewy bodies. The establishment of this project sparked
		a new collaboration with the European DLB consortium (E-DLB). By combining longitudinal
		data from E-DLB and PICC (project 4), we are poised to publish insights into the comparison
		of disease progression and the impact of dementia biomarkers across these two groups.
		initiative to increase interdisciplinary collaboration between the university and the
		hospital. This support has allowed us to recruit a researcher specializing in imaging and
		machine learning, GRAND has been presented at 2 conferences and contributes to 1 PhD.
		Link to website: The GRAND project - Helse Stavanger HF (helse-stavanger.no)
Project 6:	Project owner(s) (project	Stavanger University hospital
	leaders organisation)	
MoDAl - A new kit for early	Total budget and share	106.000 NOK up to 2022
and fast molecular	allocated to research group	
diagnosis of PD and DLB		
	Objectives and outcomes	Objectives : Develop an accessible molecular biomarker test to aid Parkinson's diagnosis.
2022-t.d.	(planned or actual) and link	Outcomes: The MoDAI project
	to website	implements a method invented in ParkDem (project 3), where we developed an assay for
		detecting aggregatable alpha-synuclein. Applying this assay to ParkWest biological samples
		(Project 1), we demonstrated its promise as an early biomarker for Parkinson's and related
		diseases. With I IO support, we've patented the method and initiated a collaboration with
		a Norwegian company (Norucox) to develop it into an accessible kit format. Jointly, we sought NEP inpovation funding in 2022 (funded 2022). Our work has been precented at
		sought with innovation funding in 2022 (funded 2023). Our work has been presented at
		international congresses and nublication is planned. The assay was also made available to
		international congresses, and publication is planned. The assay was also made available to research groups in Norway and abroad, leading to a collaboration with a national clinical

		Link to website: alpha-synuclein seeding amplification assay - Helse Stavanger HF (helse-
		stavanger.no)
Project 7:	Project owner(s) (project	Stavanger University Hospital, commissioned by The International Parkinson and
	leaders organisation)	Movement Disorder Society
Translation and validation	Total budget and share	34.250 USD, 100% allocated to the research group
of the Norwegian version	allocated to research group	
of the MDS-revised Unified	Objectives and outcomes	Objective: To develop and validate a Norwegian translation of the MDS-Unified Parkinson's
Parkinson's Disease Rating	(planned or actual) and link	Disease Rating Scale (MDS-UPDRS)
Scale	to website	Outcome: The group was commissioned by the MDS and has achieved a significant
		milestone by translating and pre-testing the English version of the MDS-UPDRS into
2019-2024		Norwegian. This clinical scale is globally recognized as the most widely used tool for
		assessing the severity of Parkinson's disease motor syndrome. Presently, a comprehensive
		validation process is underway, involving 350 patients from various regions across Norway.
		On completion, the scale will be licensed for Norwegian by the International Movement
		Disorders Society and a publication is planned.
		Link to website: MDS-Unified Parkinson's Disease Rating Scale (MDS-UPDRS)
Project 8:	Project owner(s) (project	Stavanger University Hospital
	leaders organisation)	
Early detection, prognosis,	Total budget and share	3.837.000 NOK, 100% allocated to the research group
and biomarkers of	allocated to research group	
prodromal Lewy Body	Objectives and outcomes	Objectives: To investigate the early disease mechanisms of Parkinson disease and
Diseases (the PRO-LBD-	(planned or actual) and link	dementia with Lewy bodies
study)	to website	Outcome: The ProLBD project addresses a critical gap in current knowledge concerning the
		early stages of Parkinson's and Dementia with Lewy bodies, which is an obstacle to early
2018-2028		diagnosis and optimal follow-up. In ProLBD, we have recruited at-risk healthy adults and
		are gathering important new information about the earliest signs of illness. These
		outcomes will form the basis for developing better diagnostic tools and future treatment.
		Recruitment is ongoing and follow up is planned for at least 10 years. The project
		necessitated the expansion of our collaborative network to include experts in

		neuroimaging, ophthalmology, and polysomnography. Strategically, this will also
		strengthen our group and diversifying funding opportunities.
		Link to website: The PRO-LBD-study - Helse Stavanger HF (helse-stavanger.no)
Project 9:	Project owner(s) (project	Stavanger University Hospital and University of Edinburgh
	leaders organisation)	
Effects of Bacillus subtilis	Total budget and share	749.977 GBP; 31% allocated to the research group
PXN21 on blood and gut	allocated to research group	
biomarkers in Parkinson's	Objectives and outcomes	Objectives: To access the potential of the probiotic <i>B. subtilis</i> PXN21 as a novel treatment
disease	(planned or actual) and link	for Parkinson disease
	to website	Outcomes: This multinational project, funded by the Reta Lilla Weston Trust (UK) and in
2021-2025		collaboration with the University of Edinburgh, aims to dissect the mechanism and impact
		of a probiotic (<i>B. subtilis</i> PXN21) in preventing alpha-synuclein aggregates. The project
		brings together experts in animal models, biomarkers, and clinical science from Norway,
		the UK and USA. Our group is conducting a twin-site randomized controlled trial with the
		University of Edinburgh clinical research facility. Recruitment is ongoing and outcomes
		include clinical scales, blood-based biomarkers, and the gut microbiome. Project
		completion is planned for 2024, with potential implications for larger collaborative studies
		on the impact of the probiotic on Parkinson's disease.
		Link to website: Bacillus subtilus in Parkinson's disease - Helse Stavanger HF (helse-
		stavanger.no)
Project 10:	Project owner(s) (project	Stavanger University Hospital
	leaders organisation)	
A decentralized trial of	Total budget and share	1.929.037 NOK, 100% allocated to the research group
individual video-assisted	allocated to research group	
cognitive behavioral	Objectives and outcomes	Objectives: To conduct a remote, randomized, delayed start trial to assess the
therapy for depressive	(planned or actual) and link	effectiveness of online, video-assisted cognitive-behavioural therapy (eCBT) for depressive
disorder in Parkinson's	to website	symptoms in Parkinson disease patients.
disease (ePARK)		Outcomes: The ePark study aims to recruit 120 patients with depressive symptoms,
		assigning them to two arms: immediate 10-week eCBT with concurrent treatment as usual
2021-2024		and a delayed start (14 weeks) of eCBT. Assessments will occur before treatment
		allocation, and at 14, 28, and 42 weeks to evaluate changes in depressive symptoms and
		health-related quality of life. This evidence-based online therapeutic strategy holds

	promise for significantly improving the lives of Parkinson patients with depressive
	symptoms. Recruitment is ongoing and the ePark protocol was submitted for publication in
	2022. Further, we plan to adapt this novel strategy for anxiety in Parkinson's disease.
	Link to website: www.eparkstudien.no [website in Norwegian]

Table 5. Research group's contribution to publications

Instructions: Please select 5-15 publications from the last 5 years (2018-2022) with emphasis on recent publications where group members have a significant role. **If the publication is not openly available, it should be submitted as a pdf file attached to the self-assessment.** We invite you to refer to the Contributor Roles Taxonomy in your description: <u>https://credit.niso.org/</u>.

Cf. Table 1. List of personell by categories: Research groups up to 15 group members: 5 publications. Research groups up to 30 group members: 10 publications. Research groups above 30 group members: 15 publications.

Please delete tables that are not used.

Publication 1: Title: The value of cerebrospinal fluid α -synuclein and the tau $/\alpha$ -	Authors (Please	Førland MG, Tysnes OB, Aarsland D, Maple-Grødem J, Redersen KE, Alves G, Lange J
synuclein ratio for diagnosis of neurodegenerative disorders with	members)	reaciser Ri, Alves G, Lange J
Lewy pathology	Short description	This PhD-led study investigates CSF biomarkers in Parkinson's
Journal: European Journal of Neurology		(PD), Lewy body dementia (DLB), and Alzheimer's (AD). Using
Year: 2019		a new total α -synuclein ELISA assay developed by the group,
DOI: <u>10.1111/ene.14032</u>		we measured total α -synuclein and total tau in participants
URL: <u>https://onlinelibrary.wiley.com/doi/10.1111/ene.14032</u>		from the Norwegian ParkWest and DemWest studies, and
		found that combining PD- and AD-biomarkers improves
		diagnostic accuracy for these diseases. (<u>open access</u> ; level 2)
	Research group's	Conceptualization; Data curation; Formal Analysis; Funding
	contribution	acquisition; Investigation; Methodology; Project
		administration; Resources; Supervision; Writing – original
		draft; Writing – review & editing
Publication 2:	Authors	Hiorth YH, Pedersen KF, Dalen I, Tysnes OB, Alves G
Title: Orthostatic hypotension in Parkinson disease: A 7-year	Short description	This study followed drug-naive PD patients and controls from
prospective population-based study		the ParkWest study for 7 years, assessing orthostatic
Year: 2019		hypotension (OH) frequency and features. The study found
Journal: Neurology		evidence of undertreatment of OH in early PD, emphasizing
DOI: <u>https://doi.org/10.1212/WNL.00000000008314</u>		the need for active assessment and management. (pdf
URL: <u>http://www.neurology.org/</u>		attached; level 2)
doi/10.1212/WNL.000000000008314	Research group's	Conceptualization; Data curation; Formal Analysis; Funding
	contribution	acquisition; Investigation; Methodology; Project
		administration; Resources; Writing – original draft; Writing –
		review & editing

Publication 3:	Authors	Erga AH, Alves G, Tysnes OB, Pedersen KF
Title: Evolution of impulsive-compulsive behaviors and cognition in Parkinson's disease Journal: Jounal of Neurology Year: 2020 DOI: <u>10.1007/s00415-019-09584-7</u> URL:	Short description	This PhD-led study investigates impulsive and compulsive behaviours (ICBs) in PD over 4 years. We found that ICBs are prevalent yet often non-persistent and challenge the previous assumptions about the substantial impact of ICBs on cognitive function in Parkinson's patients. (<u>open access</u> ; level 2)
https://link.springer.com/article/10.1007/s00415-019-09584-7	Research group's contribution	Conceptualization; Data curation; Formal Analysis; Funding acquisition; Investigation; Methodology; Project administration; Resources; Supervision; Writing – original draft; Writing – review & editing
Publication 4: Title: Association of GBA Genotype With Motor and Functional	Authors	Maple-Grødem J, Dalen I, Tysnes OB, Macleod AD, Forsgren L, Counsell CE, Alves G
Decline in Patients With Newly Diagnosed Parkinson Disease Journal: Neurology Year: 2021 DOI: <u>10.1212/WNL.000000000011411</u> URL: <u>https://www.neurology.org/doi/</u> <u>10.1212/WNL.000000000011411</u>	Short description	Pooling data from three cohorts from the Parkinson's Incidence Cohorts Collaboration (PICC) study , this paper reveals that <i>GBA1</i> variants in Parkinson's patients are linked to a more aggressive disease course, despite similar motor profiles at diagnosis. Simulations indicate that exclusively recruiting <i>GBA1</i> carriers in clinical trials can substantially reduce trial size, highlighting the pivotal role of genetic subpopulations in successful trial design for PD interventions. (<u>open access</u> ; level 2)
	Research group's contribution	Conceptualization; Data curation; Formal Analysis; Funding acquisition; Investigation; Methodology; Project administration; Resources; Writing – original draft; Writing – review & editing
Publication 5: Title: Genome-wide survival study identifies a novel synaptic locus and polygenic score for cognitive progression in Parkinson's disease Journal: Nature Genetics	Authors (Please highlight group members)	Liu G, Peng J, Liao Z, Locascio JJ, Corvol JC, Zhu F, Dong X, Maple-Grødem J , Campbell MC, Elbaz A, Lesage S, Brice A, Mangone G, Growdon JH, Hung AY, Schwarzschild MA, Hayes MT, Wills AM, Herrington TM, Ravina B, Shoulson I, Taba P, Kõks S, Beach TG, Cormier-Dequaire F, Alves G , Tysnes OB,

Year: 2021 DOI: <u>https://doi.org/10.1038/s41588-021-00847-6</u>		Perlmutter JS, Heutink P, Amr SS, van Hilten JJ, Kasten M, Mollenhauer B, Trenkwalder C, Klein C, Barker RA, Williams- Grav CH, Marinus I: International Constics of Parkinson
0.12. <u>www.hature.com/articles/341300.02100047.0</u>		Disease Progression (IGPP) Consortium. Scherzer CR
	Short description	This international collaboration leverages data from 3,821 PD patients over 31,053 visits to identify new genetic factors impacting the development of dementia in PD. The study reveals <i>RIMS2</i> as a key progression locus and reaffirms connections with <i>GBA1</i> and <i>APOE</i> . Notably, it also provides
		evidence for distinct genetic architectures for the progression
	Research group's contribution	of PD and its susceptibility. (<u>open access</u> ; level 2) Data curation; Funding acquisition; Investigation; Resources; Writing – review & editing
Publication 6: Title: Genome-wide histone acetylation analysis reveals altered transcriptional regulation in the Parkinson's disease brain Journal: Molecular Neurodegeneration Year: 2021 DOI: <u>https://doi.org/10.1186/s13024-021-00450-7</u> URL: <u>https://molecularneurodegen eration.biomedcentral.com/</u> <u>articles/10.1186/s13024-021-00450-7</u>	Authors	Toker L, Tran GT, Sundaresan J, Tysnes OB, Alves G , Haugarvoll K, Nido GS, Dölle C, Tzoulis C
	Short description	This regional collaboration explores histone acetylation in PD patients' brain tissue from the ParkWest study. The results highlight the role of aberrant histone acetylation and altered transcription in PD. Notably, the study suggests that Nicotinamide adenine dinucleotide (replenishment therapy using nicotinamide riboside (NR), could be a potential neuroprotective strategy for PD, and contributed to the groundwork for clinical trials of NR therapy in Norway. (open access; level 1)
	Research group's contribution	Conceptualization; Data curation; Funding acquisition; Investigation; Project administration; Resources; Writing – review & editing
Publication 7:	Authors	Erga AH, Maple-Grødem J, Alves G
Title: Cannabis use in Parkinson's disease-A nationwide online survey study Journal: Acta Neurologica Scandinavica Year: 2022	Short description	This study surveyed prevalence, attitudes, and experiences of cannabis use among members of the Norwegian PD Association patient group. One in 20 patients reported cannabis use, with associated benefits in motor function,

DOI: https://doi.org/10.1111/ane.13602 URL: https://onlinelibrary.wiley.com/doi/full/10.1111/ane.13602	Research group's contribution	 sleep, and pain. Notably, the use of cannabis was often not reported to health care professionals, arguing for a vigilant approach to non-prescribed cannabis use in clinical follow-up of patients with PD. (<u>open access</u>; level 1) Conceptualization; Data curation; Formal Analysis; Funding acquisition; Investigation; Methodology; Project administration; Writing – original draft; Writing – review & editing 	
Publication 8: Title: Association of Plasma p-tau181 and p-tau231 Concentrations With Cognitive Decline in Patients With Probable Dementia With	Authors (Please highlight group members)	Gonzalez MC , Ashton NJ, Gomes BF, Tovar-Rios DA, Blanc F, Karikari TK, Mollenhauer B, Pilotto A, Lemstra A, Paquet C, Abdelnour C, Kramberger MG, Bonanni L, Vandenberghe R, Hye A, Blennow K, Zetterberg H, Aarsland D	
Journal: Jamaneurology Year: 2022 DOI: <u>10.1001/jamaneurol.2021.4222</u> URL: <u>https://jamanetwork.com/journals/jamaneurology/</u> <u>fullarticle/2786605</u>	Short description	This PhD-led multicenter longitudinal cohort study included participants from the European-DLB (E-DLB) Consortium to assess the potential of forms of phosphorylated tau (p-tau) as biomarkers for cognitive decline in dementia with Lewy bodies (DLB). The findings suggest that measuring plasma p- tau181 and p-tau231 levels could serve as an affordable and accessible method for assessing cognitive decline in DLB. (open access; level 2)	
	Research group's contribution	Conceptualization; Formal Analysis; Funding acquisition; Investigation; Writing – original draft	
Publication 9:	Authors (Please	Szwedo AA Dalen I Dedersen KE Camacha M Bäckström D	
Title: Parkinson's Incidence Cohorts Collaboration. <i>GBA</i> and <i>APOE</i> Impact Cognitive Decline in Parkinson's Disease: A 10-Year Population-Based Study Journal: Movement Disorders	highlight group members)	Forsgren L, Tzoulis C, Winder-Rhodes S, Hudson G, Liu G, Scherzer CR, Lawson RA, Yarnall AJ, Williams-Gray CH, Macleod AD, Counsell CE, Tysnes OB, Alves G , Maple-Grødem J	
Year: 2022 DOI: <u>10.1002/mds.28932</u> URL: <u>https://movementdisorders. onlinelibrary.wiley.com</u> /doi/full/10.1002/mds.28932/	Short description	Led by a PhD candidate, this pioneering study is the first large-scale, population-based investigation into the influence of common genetic variants on cognitive decline in PD. Analysing 1002 newly diagnosed PD patients from the PICC cohorts, the study underscores the central role of <i>GBA1</i> and	

	Research group's contribution	 APOE variants in predicting cognitive decline in PD, while noting no significant effects for MAPT or SNCA. This insight lays the foundation for more personalized treatment strategies in PD. (open access; level 1) Conceptualization; Data curation; Formal Analysis; Funding acquisition; Investigation; Project administration; Resources; Supervision; Writing – original draft; Writing – review & editing
Publication 10:	Authors	Oftedal L, Maple-Grødem J, Dalen I, Tysnes OB, Pedersen KF,
Title: Association of CSF Glucocerebrosidase Activity With the Risk		Alves G, Lange J
of Incident Dementia in Patients With Parkinson Disease	Short description	Building on our prior research demonstrating the importance
Journal: Neurology		of variations in the glucocerebrosidase-encoding gene (GBA1)
Year: 2022		as risk factors for PD and PD dementia, here we analyze the
DOI: <u>10.1212/WNL.000000000201418</u>		connection between glucocerebrosidase enzyme activity and
URL:		disease course. We found that patients had reduced CSF
https://www.neurology.org/doi/10.1212/WNL.0000000000201418		glucocerebrosidase activity at the time of PD diagnosis and
		that individuals with lower enzyme activity exhibited a higher
		(Open access: Level 2).
	Research group's	Conceptualization; Data curation; Formal Analysis; Funding
	contribution	acquisition; Investigation; Methodology; Project
		administration; Resources; Writing – original draft; Writing –
		review & editing

Table 6. Please add a list with the research group's monographs/scientific books.

Please delete lines which are not used.

	Title - Authors (Please highlight group members)- link to webpage (if possible)
1	Book chapter: Parkinsons sjukdom. In: FYSS 2021 - Fysisk aktivitet i sjukdomsprevention och
	sjukdomsbehandling. Hiorth YH, Alves G, Nilsson MH (no link available)
2	Book chapter: Fysisk aktivitet vid Parkinsons sjukdom. In: FYSS 2017 - Fysisk aktivitet i
	sjukdomsprevention och sjukdomsbehandling. Hiorth YH , Borg K, Nilsson MH (no link available)
3	Book chapter: Biomarkers for cognitive impairment and dementia in Parkinson's disease
	(2015). Alves G, Pedersen KF, Larsen JP. Link to webpage
4	Book chapter: Fatigue rating scales in Parkinson's disease (2012). Alves G. Link to webpage

2.2 Research group's societal contribution

Describe the societal impact of the research group's research. Consider contribution to education, economic, societal and cultural development in Norway and internationally.

Education: Our group makes extensive contributions to education of researchers and health care professionals. These include not only formal education activities in Norway described above (1.2c), but also presentations at national and international seminars and conferences, contributions to web content, and publication of treatment guidelines (table 7, No. 1) and our own magazine MOVE (table 7, No. 2). In addition, we regularly educate patients and the public through various means, including face-to-face and online meetings and seminars, traditional and social media, and on webpages of professional and user organizations (table 7, No. 3-5).

Economic: Neurodegenerative diseases are costly for the society. Our research aims to improve diagnostics, treatment and care. This will improve prognosis and, in best case, prevent disease progression, which would reduce the costs for the society dramatically. In addition, our research fosters innovations (see table 7, No. 6), which in the future not only may save costs but also create jobs and thus stimulate economic growth.

Societal: As part of the National Advisory Unit on Movement Disorders, the group's mission is to gain and spread knowledge on Parkinson's disease and related disorders. Our research and work with the National Parkinson Registry and Biobank (table 7, No. 7) and the implementation of ParkinsonNet in Norway (table 7, No. 8) lead to new discoveries and developments that are highly relevant for the Parkinson's disease community and the society in general. We regularly advice user organizations and governmental and public healthcare authorities (table 7, No. 9), thus influencing social policies and decision-making.

Cultural: People with Parkinson's disease may experience stigma related to a range of motor and nonmotor symptoms, including cognitive and behavioral changes (e.g. impulse control disorders). With our research, educational activities and informational campaigns (table 7, No. 10), we contribute to a better understanding of the causes, consequences and optimal treatment of these problems among patients, relatives, health care professionals and the public. This again reduces the stigma related to these symptoms and the potential negative social consequences experienced by patients such as social isolation or rejection. In addition, with the remote research infrastructure that our group is developing, our research will become more accessible to people across Norway, which will further increase social and cultural diversity in our projects.

 Table 7. The research group's societal contribution, including user-oriented publications, products (including patents, software or process innovations

 Instructions:
 Please select 5–10 of your most important user-oriented publications or other products from the last 5–10 years with emphasis on recent

 publications/products.
 For each item, please use the following formatting.

 Please delete lines which are not used.
 10 fra siste 10 år hvor 5 er fra siste 5 år.

No.	Name of publication/product	Date of publication/product	Link to the document
1	Norwegian guidelines for the diagnosis and treatment	2019	Guidelines [Norwegian]
	of dystonia		
2	MOVE, magazine for healthcare professionals	2018 – to date	MOVE [Norwegian]
3	Norwegian patient handouts on various movement	2017 – to date	Norwegian patient handouts
	disorders, in cooperation with the International		
	Parkinson and Movement Disorder Society		
4	Online teaching course on Parkinson's disease and	2020	Online course on Parkinson's and nutrion [website
	nutrition for healthcare professionals, in cooperation		in Norwegian]
	with the Norwegian Parkinson Association		
5	Patient information written for, and in cooperation	Continuous contributions	Patient information on Research [website in
	with, the Norwegian Parkinson Association; here		Norwegian]
	exemplified with a link to the topic "Research" on the		
	user-organization's webpage		
6	Patent for new biochemical detection method	2022	PDF attached: P31693SE Patent application
			extract
7	Norwegian Parkinson Registry and Biobank, the	2016 – to date	Norwegian Parkinson's Registry and Biobank -
	national medical quality registry established to		Helse Stavanger HF (helse-stavanger.no)
	improve patient care and equal access to healthcare		
	services		
8	ParkinsonNet Norway - online "healthcare finder" to	2020	Healthcare finder [website in Norwegian]
	connect users with nearby physiotherapists,		
	occupational therapists, speech therapists and nurses		
	with training and expertise in Parkinson's disease and		
	related disorders		
9	Advice to the public/user organisations	2021	Advice on Parkinson's and covid-19
10	Podcast on impulse control disorders - as part of a	2021	Podcast on impulse control disorders [website in
	larger informational campaign - in collaboration with		Norwegian]
	the Norwegian Parkinson Association		

3. Challenges and opportunities

Information about the strengths and weaknesses of the research group is obtained through the questions above. In this chapter, please reflect on what might be the challenges and opportunities for developing and strengthening the research and the position of the research group.

We recognise several potential challenges and opportunities:

Economic Challenges:

- The National Advisory Unit on Movement Disorders will experience a gradual reduction in core funding from 2023, due to a reorganization of National Advisory Units into National networks. Although the administrative unit plans to compensate with increased funding, securing additional funding for new permanent research positions in the group remains uncertain.
- A significant and increasing proportion of our research funding is project-based. To achieve our group's ambitions for growth, we must further augment the share of project-based funding.
- Despite our strong national and international standing, the evolving landscape of Norwegian research environments is intensifying competition for funding.

The Research Group and Resources Challenges:

- Our field is complex, requiring access to highly skilled personnel from multiple disciplines. Recruiting and retaining qualified and promising clinical and basic researchers present challenges.
- Our research group relies on administrative unit support services (see 1.2d and 1.5b). Anticipating future challenges, we expect a growing demand for these services.

Operational Challenges:

- A new hospital is under construction (opening 2025) in proximity to the University of Stavanger. We see a risk of fragmentation of the clinical environment (which will move to new facilities) and our research group (which will stay in the current facilities for the foreseeable future).
- Our research is patient-centered. The Norwegian healthcare system is currently experiencing limited resources and challenges in clinical operations (e.g. long waiting lists). This makes it more difficult to recruit and retain study participants, presenting a significant challenge to our research.

Economic Opportunities:

- Following our long-term strategy for 2012-2022, we have achieved substantial growth in our research group, output, facilities, portfolio, and collaborations. This has clearly strengthened our position both scientifically and to obtain funding from external sources including NFR and EU.
- The field of neurodegenerative diseases and 'brain health' is garnering increasing interest among society, decision-makers, and funding organizations. This growing awareness is expected to lead to enhanced allocations for research in our field, both nationally and internationally.

The Research Group and Resources Opportunities:

- In a collaborative effort with other neuroscience groups at Stavanger University Hospital, we are establishing a "Centre for Brain Health." This joint effort will foster independence and enhance attractiveness for researcher recruitment.
- We will further strengthen our collaborations with the University of Stavanger, which can provide new opportunities for recruiting early-stage researchers.
- We have well-established international collaborations and a focus on promoting mobility, which will create new avenues for recruiting individuals with diverse backgrounds and expertise.

Operational Opportunities:

- Our strategy has evolved to include a smart and decentralized research infrastructure, which we foresee will address current clinical challenges, enhance participant recruitment, and augment the quantity and quality of data. This will increase our chances of outstanding publications, extend our collaborative network, and increase funding opportunities.
- The Parkinson Registry and Biobank and ParkinsonNet each present a unique resource to conduct and apply our research on Parkinson's disease on a national scale, opening new opportunities for projects, collaborations, funding, and knowledge development in Parkinson's disease research.