



Annual Report 2019

The Nordic Cancer Union

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Appendix 1 The NCU financial statement 2019



Nordic Cancer Union
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NCU in short



Another year of fruitful collaboration in NCU has gone by. It is amazing how many similarities we have between our countries and how much added value it gives us to exchange experiences and challenges. Indeed, to me, our mutual work in the framework of NCU is international cooperation at its best.

Jesper Fisker
NCU chairman

The Nordic Cancer Union (NCU) was founded in 1949 to enhance collaboration between the cancer societies in the Nordic countries. Its main aim is co-operation on relevant strategic issues, exchange of experiences, and to be a forum for inspiration for the Cancer Society of Finland, the Icelandic Cancer Society, the Swedish Cancer Society, the Norwegian Cancer Society, the Faroe Cancer Society and the Danish Cancer Society.

Strategic Plan 2018 – 2020

In August 2017, the NCU Board decided that the existing Strategic Plan 2015-2018 would continue in the period 2018-2020. The decision was taken on the basis, that NCU had a thorough review of the NCU statutes in 2015-2016, and that NCU's statutes are therefore up-to-date, form a framework with a through line that allows NCU to raise issues and act if / when there is desire, and will.

Chair and secretariat

A board comprising representatives of each of the member organizations directs the NCU. The chairman of the board is responsible for the NCU's function during a three-year mandate period. The strategies and priorities for the NCU are stipulated by the board and should be valid during the three year alternating chairmanship of the member organizations.

The Danish Cancer Society is responsible for the NCU chairmanship and the NCU secretariat 2018 – 2020.

NCU finances, including research grants

The total income of the NCU in 2019 was € 1.006.205. Membership fees accounted for € 1.005.585 and interest income on bank accounts was accounted for € 620.

Every year the Nordic Cancer Union grants € 750.000 to cancer research. In 2019, the NCU awarded 15 grants totalling € 750.000 to cancer research. Grants ranged from € 40.000 to € 76.000.

NCU 2019 activities



Members of the NCU board 2019

In 2019 the chairmanship of the NCU, coordinated the collaborative activities and organized

- three NCU board meetings. The Chairman of the NCU Scientific Committee was invited to meet the NCU Board in November 2020.
- one NCU Scientific Committee meeting.
- workshops on Cancer Research Communication to the General Public and on Inequality.

Inspirational presentations on selected topics of current common interest

As being a forum for exchange of experiences and mutual inspiration for the Cancer Society of Finland, the Icelandic Cancer Society, the Swedish Cancer Society, the Norwegian Cancer Society, the Faroe Cancer Society and the Danish Cancer Society each NCU Board meeting includes inspiring presentations on selected topics of the NCU members current common interests. Topics have been:

Data ethics in relation to social media - pitfalls, awareness points and opportunities

Privacy and the individual's right to control their own data are crucial for trust in the public sector and among organizations as well as private companies. Data ethics is becoming a social responsibility, just as being green today is. The presentation included a description of what data ethics are, examples of data ethics and individual data control, and recommendations for data ethical tools and services that organizations can use themselves. The presentation focused on non-profits, pitfalls, awareness points and opportunities.

Inequality in survival after cancer

Major progress in cancer treatment has been made in recent years, but not all patients benefit equally. Inequality is evident at every stage of the cancer journey, and the problem is increasing.

The newly established Danish Research Center for Equality in Cancer focuses on how socially weak cancer patients also benefit from the progress in cancer treatment and care.

There is a lack of knowledge in several areas, but there are unique opportunities to fill knowledge gaps at Nordic level. The following areas are important and suitable for Nordic action areas:

- Less common cancer types
- After primary cancer treatment
- Vulnerable / marginalized groups
- Patient related factors, such as waiting time, lifestyle, QoL, need for and use of rehabilitation & palliation
- Development of preventive strategies acknowledging that different groups have different health strategies
- Evaluation and monitoring of structural changes implemented, i.e. the cancer pack-ages, new treatments etc.

Problems in relation to broad implementation of the knowledge have to be addressed. One challenge is how to properly communicate without hurting target audiences.

Ethics and Precision Medicine with focus on cancer patients

Precision medicine is an approach to patient care that allows selecting treatments, that are most likely to help patients based on a genetic understanding of their disease. The idea of precision medicine is not new, but recent advances in technology especially for whole genome sequencing (WGS) have greatly improved the use of genetics in a clinical setting. WGS of tumours has the potential to identify changes in genes and pathways and therefore subdivide patients with different treatment options.

Sometimes cancer is a hereditary disease, where WGS of tumours and blood samples can identify germline variants in genes such as the breast-ovarian cancer genes *BRCA1* and *BRCA2*. This will also have implications for family members, who might be carriers of these genetic variants. For healthy family members it is important to know, if these cancer diseases can be prevented or treated at an early stage, so survival will be improved. Other ethical issues could be stigmatizing or genetic discrimination of gene carriers and who should/could inform relatives about genetic testing.

Sometimes genetic variants are found in genes, that will predict an increased risk of another disease, where prevention and/or treatment is not possible. This creates ethical dilemmas such as the right not to know and respecting patient autonomy. Patient consent is under pressure when WGS is a prerequisite for precision medicine. What if the patient wants to opt out of WGS – will that result in a non-optimal treatment – and is it possible to opt out, when WGS is an integrated part of diagnostics? Where is the right balance between patient autonomy and being part of a society?

Another issue is the classic dilemma of prophylaxis versus treatment and how to prioritize new expensive treatment, when the resources are limited.

Cancer as existential and spiritual turning point in life

Facing serious illness as cancer some people experience an "existential and spiritual shock", that can change the perception of meaning of life and beliefs. During the "cancer-journey" many patients will from time to time have different existential considerations and questions for example "Why me?" "Will I die from this disease?" "What have I done to deserve this? - Is it my own fault?"

During the cancer journey, many patients will experience existential restlessness and anxiety. Existential restlessness and anxiety are the mentally healthy persons normal reaction to the loss of control. Existential anxiety is one of the most common reactions to cancer (and other severe diseases) and one of the most influential symptoms to patients, which at the same time is the least bespoken symptom from doctors and nurses.

Existential restlessness and anxiety become clear at different times during the cancer-journey. At the time of diagnosis (why me? – will I survive?), after finishing treatment (who am I now?) If cancer returns and during palliative care (How is it to die? What is death?).

In order to help best people with cancer, it is essential, that the health professionals have insight into and understanding of the variability of values and can support people with their individual values. The lecture shed light on how values differ from previous (the traditional and modern society) to today (the late modern society) and discussed what significance it has for the helpers meeting with cancer patients.

Newly developed educational initiatives were presented: Existential Laboratory ExLAB. ExLAB is a new educational initiative between supervision and traditional staff training, addressed at health professionals. The main purpose of the course is to better prepare the health professionals for conversations with patients about basic existential/spiritual themes.

NCU workshops 2019

NCU workshop on cancer research communication

All members of the Nordic Cancer Union fund cancer research. In all Nordic countries, funding from the cancer societies has been important for the level and quality of cancer research.

The possibility to fund cancer research is an important factor for many, who support the cancer societies. At the same time all cancer society's report, that there is a challenge to present results/outcome from research. For different reasons results and impact from cancer research can be hard to measure and difficult to communicate.

On this background based on an initiative from the Norwegian Cancer Society the board of the NCU decided to arrange a workshop on research communication. The primary purpose of the workshop was to exchange experiences and share best practice between the Nordic cancer societies.

The workshop was arranged June 4, 2019 in Oslo, Norway, at the Norwegian Cancer Society's Science Center. All organizations participated in the workshop.

In addition to prepared presentation from each cancer society, there was plenty of room for dialogue and for sharing experiences between the participants.

All participants concluded, that it was very useful to have this type of arena for sharing experiences. Several gave the impression, that they had learned experiences, which they will follow up in their representative organization. There was also a common interest to keep this network alive for potential further use.

NCU workshop on inequality in the Danish Cancer Society

As part of the Presidency of the Nordic Cancer Union, the Danish Cancer Society held an all-day workshop on inequality in cancer for all member countries on September 4, 2019.

The background for the workshop was the knowledge that improvement in the field of cancer does not benefit everyone equally. People, who live alone, or who have short education and low income, are at higher risk of getting cancer, and they have less probability of surviving a cancer disease compared to people who are cohabiting or who have a longer education and higher income. The social gradient exists throughout the cancer course, and unfortunately, the inequality in cancer is increasing.

The purpose of the workshop was to share knowledge and experiences in the Nordic cancer associations from the work within reducing inequality in cancer. The Danish Cancer Society has made a white paper on cancer inequality in Denmark. One of the authors of the white paper, PhD student Maja Halgren Olsen, gave a presentation on existing knowledge in the field. At the workshop, all the representatives from the individual cancer associations were invited to talk

about activities in the field in their own countries. There was also a discussion and exchange of ideas on how the fight against inequality in cancer could be developed.



Participants at the NCU workshop on inequality in the Danish Cancer Society September 4, 2019

NCU Strategic Funds and projects

The Nordic Cancer Union provides funding for strategic projects of high standard within the field of cancer amounting to 250.000 euros annually. The projects funded by the NCU meet strict requirements, with priority given to projects and initiatives that reflect the current general strategy of the NCU and have added Nordic value. Regulations and guidelines were adopted by the board of the Nordic Cancer Union in 2016, and came into use immediately.

Researchers working in two or more Nordic countries must be involved in the project. The projects applied for must have cancer relevance, be uniquely suited to be carried out within the Nordic countries, and the effect of collaboration should be synergistic.

The NCU Board decided to support four strategic projects in 2019:

- NORDCAN – cancer statistics for the Nordic countries
- Cancer epidemiology and screening participation among non-western immigrant women in the Nordic countries
- Nordic Adolescents and the New Nicotine Market
- EFPN – European Fair Pricing Network

New confirmed financial support 2019

NORDCAN Cancer Statistics for the Nordic countries	2019 – 2021	176.706 euros
Cancer epidemiology and screening participation among non-western immigrant women in the Nordic countries	2020 -2021	150.000 euros
Nordic Adolescents and the New Nicotine Market	2020 – 2021	150.000 euros
EFPN – European Fair Pricing Network	2020 – 2021	70.000 euros
Total confirmed support		546.706 euros

NORDCAN Cancer Statistics for the Nordic countries

The NCU Board decided to support NORDCAN during 2019 – 2021. January 1st 2019, the secretariat of NORDCAN moved from the Danish Cancer Society to the Cancer Registry of Norway. One of the main tasks of the new secretariat the next three years, in addition to facilitating the existing NORDCAN-cooperation, is to lead the project of the upcoming transition, modernization and harmonization of the whole NORDCAN-platform. To secure continuous sharing of data between the Nordic countries, the secretariat and IARC, there is a need to move from a centralized data processing in the secretariat to localized data processing in each Nordic country.

The main tasks of the NORDCAN-group, the IT-group and the secretariat is to make all necessary specifications for both the harmonization and quality assurance of the localized data processing and for a new web platform.

Cancer epidemiology and screening participation among non-western immigrant women in the Nordic countries

There is significant geographical variation in cancer incidence and mortality worldwide. Cervical cancer is a clear example of a global health disparity with about 90% of the disease occurring in low or medium HDI regions. Screening has been shown to reduce mortality from breast and cervical cancer. In the Nordic countries with population-wide screening programs, attendance is suboptimal in women with foreign background. Barriers for screening in these population groups have been examined so far only to a limited extent.

In the Nordic countries, there are national population, cancer and screening registries with high completeness. Thus, the Nordic countries provide a unique data source to follow and monitor cancer incidence, cancer mortality and screening participation in female populations with foreign origin.

This study focuses particularly on women born abroad and women born in the Nordic countries to immigrant parents. In the Nordic countries combined, the share of people with foreign background is substantially higher than in Finland alone. Population with foreign background is expected to grow in all the Nordic countries in the near future.

The aim of this research is to estimate cancer incidence, mortality and survival, and to identify possible barriers to cancer screening among women with non-western background in the Nordic countries.

Nordic Adolescents and the New Nicotine Market (NADNIC)

The project concentrates on adolescents aged 14 to 17 where the risk of getting addicted to tobacco and other nicotine products is high. Adolescents like to experiment and adopt behaviours belonging to the adult world. New trends like electronic cigarettes interest them while long-term risks, even if known, are not a concern. Adolescents are potential new consumers of e-cigarettes, heated tobacco as well as chewing tobacco and snus, usually containing highly addictive nicotine and having adverse health effects.

Knowing and understanding adolescent behaviour in the present Nordic context is needed for creation of effective preventive measures and policies.

Recommendations for NCU will be formulated.

EFPN – European Fair Pricing network

NCU has joined EFPN – European Fair pricing network as a founding member.

The European Fair Pricing Network (EFPN) aims at achieving fair prices of cancer medicines and, more broadly, at working towards a pharmaceutical market, which produces accessible and truly innovative medicines for patients. EFPN includes a research network as well as advocacy.

EFPN is a three years scheduled project founded by Dutch Cancer Society, Irish Cancer Society, Kom Op Tegen Kanker – Belgium, Pasykaf – The Cyprus Association of Cancer Patients & Friends, Swiss Cancer Society and NCU Nordic Cancer Union.

Table 1– Overview Strategic Project Grants 2015 – 2021

Strategic projects overview										
<i>Project overview - Agreed by the Board of NCU, in May 2017 - changed in Januar 2020</i>										
<i>All amounts in EURO</i>										
			Total support	Planned in 2015	Planned in 2016	Planned in 2017	Planned in 2018	Planned in 2019	Planned in 2020	Planned in 2021
1. Confirmed financial support	Notes									
Secretariat for Nordic NECT	1	148.000	48.000	50.000	50.000					
UICC/IARC summer school	2	32.800	16.400	16.400	0					
NORDCAN	3	106.500		35.500	35.500	35.500				
Nordic Summer School in Cancer Epidemiology	4	92.300			46.150	46.150				
Pakkeforløb i de nordiske lande	5	70.000					35.000	35.000		
Nordic Summer School in Cancer Epidemiology 2019	6	92.300						77.300	15.000	
Canceromkostninger i de nordiske lande	7	118.500						59.250	59.250	
NORDCAN - Cancer statistics for the Nordic countries.....	8	176.706						57.281	58.887	60.538
Tobacco Products, snus and e-cigarettes	9	150.000							75.000	75.000
Socioeconomic inequality and cancer	10	150.000							75.000	75.000
EFPN	11	70.000							30.000	40.000
Total confirmed support		1.207.106	64.400	101.900	131.650	116.650	228.831	313.137	250.538	
			Total support	Actual pay-ments 2015	Actual pay-ments 2016	Actual pay-ments 2017	Actual pay-ments 2018	Actual pay-ments 2019	Actual pay-ments 2020	Actual pay-ments 2021
2. Actual payments										
Secretariat for Nordic NECT	1	148.000				98.000	50.000			
UICC/IARC summer school	2	32.800		13.227	14.137	-3.677				
NORDCAN	3	106.500				71.000		35.500		
Nordic Summer School in Cancer Epidemiology	4	92.300				92.300	-18.300			
Pakkeforløb i de nordiske lande	5	70.000					35.000		35.000	
NORDCAN - Cancer statistics for the Nordic countries.....	8	176.706						57.281		
Total actual payments		626.306	13.227	14.137	257.623	66.700	92.781	35.000	0	
Notes:										
1. Confirmed on a Board Meeting in Helsingör in September 2015										
2. Confirmed on a Board Meeting in Reykjavik 22 May 2015 and revised 17 February 2017										
3. Confirmed on a Board Meeting in Oslo 19 February 2016										
4. Confirmed on a Board Meeting in Copenhagen 25 November 2016										
5. Confirmed on a Board Meeting in Copenhagen 19 February 2018										
6. Confirmed on a Board Meeting in Copenhagen 24 October 2018										
7. Confirmed on a Board Meeting in Copenhagen 24 October 2018										
8. Confirmed on a Board Meeting in Copenhagen 8 May 2019										
9. Confirmed on a Board Meeting in Copenhagen 13 November 2019										
10. Confirmed on a Board Meeting in Copenhagen 13 November 2019										
11. Confirmed on a Board Meeting in Copenhagen 13 November 2019										

			Total support	Planned in 2015	Planned in 2016	Planned in 2017	Planned in 2018	Planned in 2019	Planned in 2020	Planned in 2021
3. Unpaid confirmed financial support	Notes									
Pakkeforløb i de nordiske lande	5		70.000					35.000		
Nordic Summer School in Cancer Epidemiology 2019	6		92.300					77.300	15.000	
Canceromkostninger i de nordiske lande	7		118.500					59.250	59.250	
NORDCAN - Cancer statistics for the Nordic countries.....	8		176.706						58.887	60.538
Tobacco Products, snus and e-cigarettes	9		150.000						75.000	75.000
Socioeconomic inequality and cancer	10		150.000						75.000	75.000
EFPN	11		70.000						30.000	40.000
Total confirmed support			827.506	0	0	0	0	171.550	313.137	250.538
4. Unapproved applications to be discussed	Notes		Total support	Planned in 2015	Planned in 2016	Planned in 2017	Planned in 2018	Planned in 2019	Planned in 2020	Planned in 2021
Total unapproved applications			0	0	0	0	0	0	0	0
			Total support	2015	2016	2017	2018	2019	2020	2021
Total unpaid and unapproved (3 og 4)			827.506	0	0	0	0	171.550	313.137	250.538

NCU Research Cancer Funding

NCU funding provides a very valuable basis for establishing professional networks across the Nordic countries. This is important, as the Nordic public health care system and registers provide research possibilities rarely found elsewhere. In this way, the NCU funding can serve also as seed money for joint applications to other funding agencies.

The NCU funding makes it possible to undertake clinical studies not of direct interest for the drug industry, e.g. testing of new surgical procedures. Several applications come from epidemiologists utilizing the Nordic population- and health registers. As an example, the NCU has now for many years supported the NOCCA study where combined data on occupation, industry and cancer incidence make it possible to identify cancer risks related to social position and work place.

NCU Scientific Committee recommendations 2019

The tasks of the committee are to assess scientific grant applications, secure high scientific quality and formulate recommendations regarding the applications to the Secretaries-General for their decisions on grants, to give consultation concerning strategic projects regarding research to the Secretaries-General for their decisions on grants, and to evaluate funded research and follow-up on the application of the results in the Nordic countries. Each year 750.000 euros are granted for cancer research. The secretariat of the committee is located at the Danish Cancer Society. The NCU has been awarding research grants since 1989.

The scientific committee comprises one member with scientific competence from each member country appointed by the NCU Board after recommendations from the national cancer societies.

Members of the NCU Scientific Committee 2019-2021

Denmark:

Elsebeth Lynge, Chairman of committee, Professor, mag.scient.soc, Department of Public Health, University of Copenhagen

Finland:

Klaus Elenius, Ph.D., Professor of medical biochemistry, University of Turku

Sweden:

Klas Kärre, Ph.D., Professor of Molecular Immunology, Dept. of Microbiology, Tumor and Cell Biology, Karolinska Institute

Norway:

Tom K. Grimsrud, Ph.D., Senior Researcher, Cancer Registry of Norway, Institute of Population-based Cancer Research, Dep. of Research

Faroe Islands:

Johan Paulsen, Consultant urologist, Department of Urology, Aalborg University Hospital, Denmark and Part time consultant urologist Kings College Hospital, London

Iceland:

Eiríkur Steingrímsson, Professor, Department of Biochemistry and Molecular Biology, Faculty of medicine, University of Iceland

Report from the NCU Scientific Committee

The annual NCU Scientific Committee (SC) meeting was conducted in Copenhagen on 30 October 2019. The Nordic Cancer Union (NCU) received 29 grant applications in 2019.

The committee recommended that 15 projects are granted by the NCU Board. A list of the projects for which funding is recommended is presented on pages 16-18. The committee's assessment is based on scientific quality, quality of researchers, level of Nordic synergy, and relevance to NCU's strategy.

Table 2 provides an overview of the number of applications received and the level of funding granted from 2016 to 2019.

Table 2: Number of applications and level of funding granted

	2019	2018	2017	2016
Number of applications received	29	30	42	34
Number and ratio (%) of applications funded	15 (53%)	16 (53 %)	19 (45 %)	16 (47 %)
Total amount of funding applied for (€)	3,441,605	4,432,625	4,042,386	3,221,733
Total funding granted (€)	750,000	750,000	750,000	750,000

Conflict of interest in the evaluation process

The chairman of the SC assigned two main reviewers for each application. Three members had a conflicting interest, and therefore, they left the room during the evaluation and did not participate in the assessment and scoring of those applications.

Quality of applications

The number of applications was low compared to previous years (2019:29, 2018:30, 2017:42, 2016:34, 2015:41, 2014:35, 2013:42, and 2012:30). In general, the committee found the quality of the applications to be good.

NCU received applications for 11 on-going and 18 new projects. SC recommends 10 on-going and 5 new projects for funding in 2019.

LOCATION OF PRINCIPAL INVESTIGATOR

Figure 1 shows the number of applications from each of the Nordic countries in 2019 (determined by the workplace location of the principal investigator). Figure 2 shows the total number of grant applications received by the NCU from 2016 to 2019.

Figure 1: Number of applications (recommended and not recommended) by location in 2019

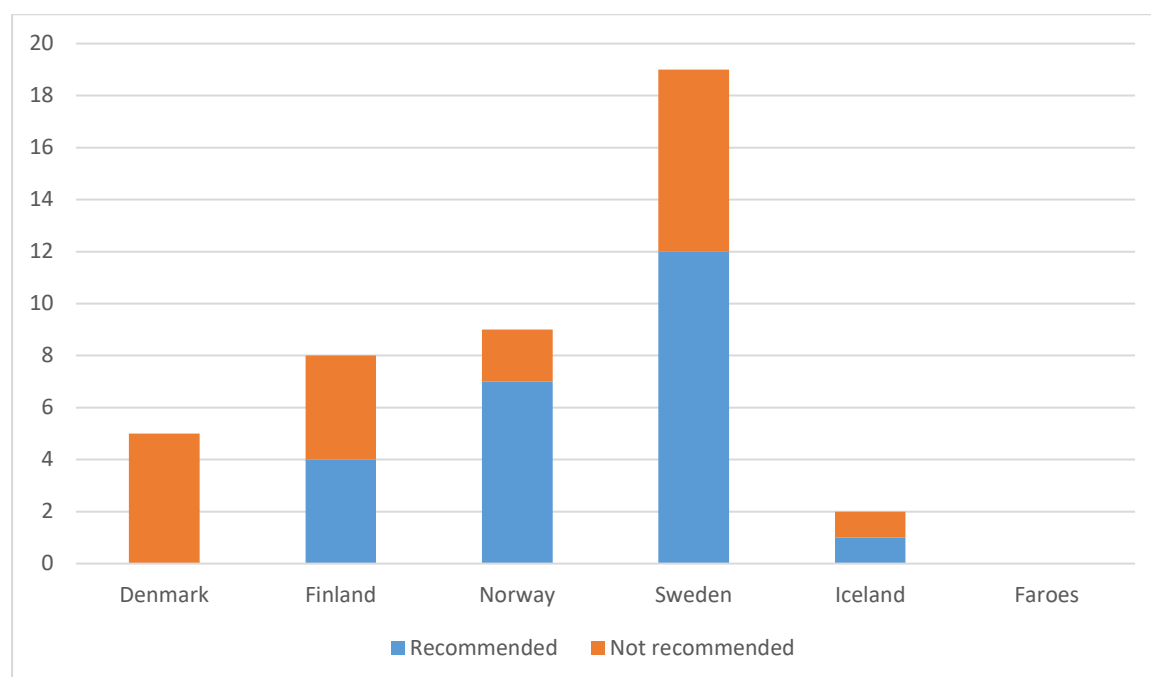


Figure 2: Total number of applications by location from 2016 to 2019

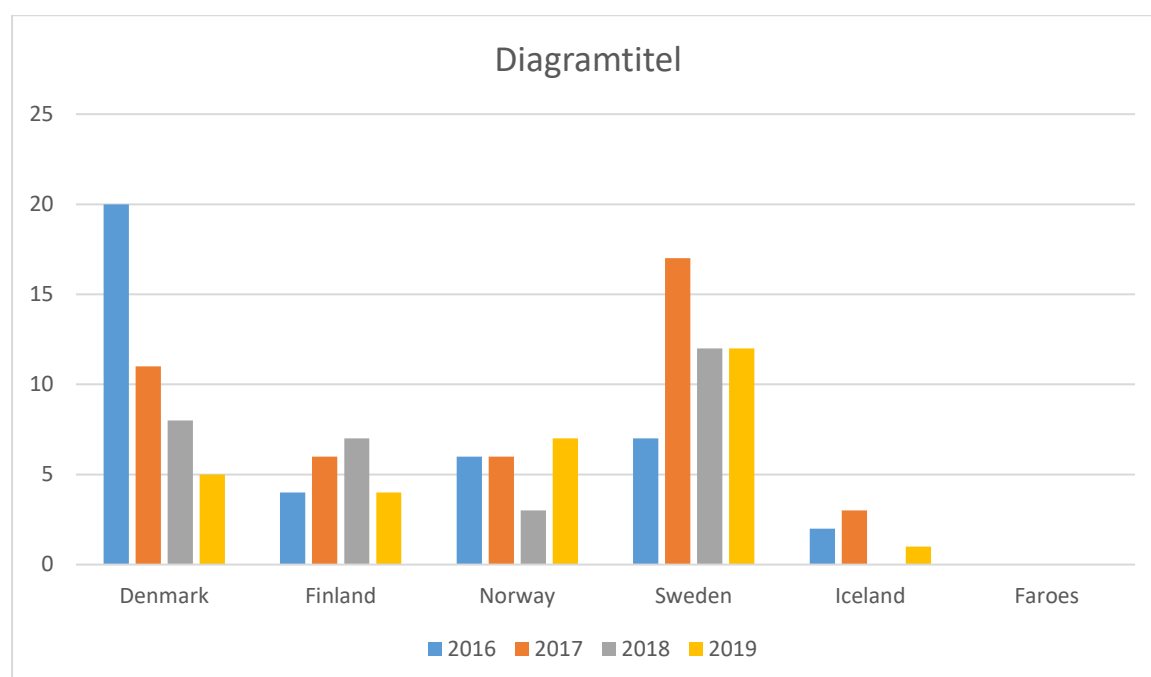


Table 3: Projects recommended to the NCU Board for funding in 2019

Principal Investigator	Project title	Project workplace (principal investigator)	Applied amount	Recommended amount
Asgeir Store Jakola	Beyond Observed Lesion Diameter (BOLD) glioblastoma surgery: a Nordic randomized controlled trial	Neurosurgery, Sahlgrenska University Hospital	80.000	50.000
Björn Nilsson	Genetic predisposition for multiple myeloma: clinical impact of recently identified risk variants	Department of Laboratory Medicine, Lund University	100.000	50.000
Henrik Falconer	Robot-assisted approach to cervical cancer (RACC): an international multi-center, open-label randomized controlled trial	Patient Area Pelvic Cancer, Theme Cancer, Karolinska University Hospital	59.000	59.000
Eero Pukkala	New wave of joint Nordic studies on work and cancer	Finnish Cancer Registry	202.000	50.000

Jesper Lagergren	The risk of oesophageal and gastric cancer after eradication of Helicobacter pylori	Molecular medicine and Surgery, Karolinska Institutet	81.725	60.000
Jennifer Harris	Genetic Epidemiology and Familial Risk of Cross-Cancer Associations: A Nordic Twin Study III	Health Data and Digitalization, The Norwegian Institute of Public Health	50.000	40.000
Jana de Boniface	Survival and axillary recurrence after sentinel node-positive breast cancer without axillary lymph node dissection: the randomized SENOMAC trial.	Dept. of Molecular Medicine and Surgery, Karolinska Institutet	190.379	76.000
Satu Mustjoki	Immunological monitoring of therapy response in chronic myeloid leukemia by the Nordic CML study group (NCMLSG)	Hematology Research Unit, University of Helsinki	100.000	65.000
Sigurdur Yngvi Kristinsson	Comorbidity in patients with multiple myeloma	Faculty of Medicine, University of Iceland	60.000	40.000
Cecilie Hveding Blimark	Treatment and survival in multiple myeloma in the Nordic countries; collaborative registry studies within the Nordic Myeloma Study Group	Nordic Myeloma Study Group (NMSG), Real World Data Group within NMSG at Sahlgrenska University Hospital Gothenburg Sweden	128.000	40.000
Karin Smedby	Life after Lymphoma - how can we individualize treatment and care to reduce complications and improve lymphoma survivorship in the Nordic countries	Karolinska Institutet, Medicine Solna	67.012	40.000
Ahti Anttila	Comparing cervical cancer screening in the Nordic countries: Transition from cytology to HPV testing	Mass Screening Registry, Finnish Cancer Registry/ Cancer Society of Finland	50.000	40.000

Mats Jerkeman	Mantle cell lymphoma - a comprehensive Nordic initiative to improve patient outcome	Oncology, Lund University	197.400	40.000
Bo Terning Hansen	Risk factors for pre-cancer and cancer: Registry follow-up of a population-based cohort of 118.000 women surveyed in Denmark, Iceland, Norway and Sweden	Department of Research, Cancer Registry of Norway	70.000	40.000
Kim Sverker Pettersson	Nanoparticle aided glycovarian biomarkers for the early detection of epithelial ovarian cancer (3rd year application)	Department of Biochemistry, Division of Biotechnology, University of Turku	80.000	60.000

The recommendations from the Scientific Committee was approved by the NCU Board 13. November 2019.

NCU member information



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