



Annual Report 2018

The Nordic Cancer Union



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Appendix 1 The NCU financial statements 2018



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NCU in short



When I was young – many years ago – I thought, that Nordic countries and Nordic cooperation as second to the European cooperation in the EU. I have changed my mind - our Nordic societies and welfare models have so many similarities, that the close cooperation between our countries is extremely fruitful.

*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 NCU secretariat was transferred from the Icelandic Cancer Society and the NCU Research Administration from Norwegian Cancer Society to the Danish Cancer Society taking over the NCU chairmanship on 1. January 2018.

NCU finances, including research grants

The total income of the NCU in 2017 was € 918.980. Membership fees accounted for € 919.512 and interest income on bank accounts was accounted for (€ 533).

Every year the Nordic Cancer Union grants € 750.000 to cancer research. In 2018, the NCU awarded 16 grants totalling € 750.000 to cancer research. Grants ranged from € 30.000 to € 50.000.

NCU 2018 activities

In 2018 the chairmanship of the NCU, coordinated the collaborative activities and organized three NCU board meetings, one NCU Scientific Committee meeting and a joint meeting of the board and the scientific committee.

Call for mutual recognition of clinical ethical approval in the Nordic countries

In February 2018 the NCU issued a call for mutual recognition of ethical approval for clinical studies in the Nordic countries.

The overall aim of the call was to facilitate the joint conduct of clinical studies in the Nordic countries. Increasing the number of clinical studies are important for improvement of treatment and care for cancer patients in the Nordic countries. The NCU see a huge potential for more clinical studies in the Nordic countries and the need to make it easier to implement such studies. The call is supported by The Danish Cancer Society, The Icelandic Cancer Society, The Faroese Cancer Society, The Cancer Society of Finland, and The Norwegian Cancer Society. For more information please contact Ole Alexander Opdalshei, Deputy Director General at The Norwegian Cancer Society ole.alexander.opdalshei@kreftforeningen.no

Call for mutual recognition of ethical approval in the Nordic countries

The Nordic Countries as an arena for clinical research

It is well established that the potential for further collaboration regarding clinical trials in the Nordic countries has a huge potential. Each of the Nordic countries has on a global scale a small population, but the total number of inhabitants in the Nordic countries are 26 million people. This together with the facts that we have a strong public health care systems, good quality registers, and high quality researchers used to collaborate makes the Nordic countries an excellent arena for improving health care through clinical research

From a patient perspective, access to clinical trials is important for several reasons. It gives better care for cancer patients today, and better treatment for tomorrow's patient capitalising on the most recent development in all aspects of care

Mutual recognition of ethical approval

Our experience based on contact and feedback from clinicians and researchers shows us that today's system where there is a need to obtain ethical approval in each country is time- and resource demanding. Therefore a barrier for clinical trials. The Nordic countries share very similar moral values, cultures and health care and legal systems. Protecting personal data from 2018 follows in all Nordic countries the EU General Data Protection Regulation, with the intention of a one-stop shop for approval of data collection and use. This gives us a unique opportunity to a similar solution for ethical approval in the Nordic countries. We acknowledge the complexity in the ethical legislation on biomedical research and its ethical pre-evaluation and the need for proper and clear information in a native language for data subjects.

On this background, the Secretary Generals in the cancer leagues calls for mutual recognition of ethical approval in the Nordic countries. If a clinical study receives a clinical approval in one of the Nordic countries this should be accepted in the other Nordic countries, given the information to the data subject is clear and unambiguous in the native language.

This call is in line with the conclusion in the report written by Bo Könberg on “The Future of Nordic Co-Operation on Health”.

Inspirational presentations on selected topics of current common interest

Each NCU Board meeting includes inspiring presentations on selected topics of the NCU members current common interests. Topics have been:

- **Clinical studies in the Nordic countries**

The childhood cancer research network (NOPHO) is as an example of successful Nordic co-operation within clinical research. NOPHO has over the years evolved into a large collaborative network in the Nordic countries (now including 2 Baltic countries). The network today also receives support for their research from the Novo Nordisk Foundation and Nordforsk.

The following keywords are of importance in order for Nordic co-operation on clinical research to succeed

- necessary infrastructure
- willingness to cooperate
- recognizing of that it is time consuming
- recognition and handling of various legal restrictions in the Nordic countries, among other things in relation to requirements for consent
- well-functioning website, as a platform for all communication in the collaboration

- **DCCC – Danish Comprehensive Cancer Center**

The establishment of the Danish Comprehensive Cancer Center (DCCC) is a part of the Danish government Cancer Action Plan IV.

The purpose of DCCC is to create optimal conditions for Danish cancer research by promoting cooperation and coordination of cancer research within Denmark as well as increasing access to international partnerships and funding. In addition, the centre helps to spread new knowledge and new treatment methods faster and more systematically across the country, thus shortening the path from research to clinical practice. In this way, DCCC contributes to optimise cancer treatment in Denmark.

DCCC combines management and professional capacities within cancer and healthcare in Denmark into a national virtual centre for cancer research and treatment. The centre is composed of individual university hospitals and research institutes and is organised with a Governance Board, a Steering Committee and a Scientific Council. The national Secretariat for DCCC is located in Aarhus.

- **Alternative treatment and medicines, including cannabis**

There is a large and increasing need for evidence-based information on alternative treatment to cancer patients. To give patients a professional basis to make decisions information must be based on an evidence-based approach, such as:

- Basic literature search on the individual subjects/treatments
- Status of research in experimental treatments
- Knowledge from clinical studies about effect, side effects and interaction with treatment and/or other medication
- Does our recommendations match international (eg Nifab, Memorial Sloan Kettering)

There is a need for continuous development of information on alternative treatment at the websites of the national cancer societies and developing new forms of communication on alternative treatment, including video, lectures, etc.

Advices to patients to consider before using alternative medicines are:

- What is your purpose of using alternative treatment?
It is important that patients consider the hopes they have towards the effect/results the alternative treatment they seek.
- How often and how long will you use it?
As a patient, there are many things they have to invest in, both time and energy wise, and in the light of what alternative treatment can offer the patient during treatment it might not/should not have first priority.
- Are there risk of side effects? And can you use it at the same time as your cancer treatment?
It is very important to ensure patient safety. Alternative treatments can have side effects and some have effect on the cancer treatment that the patient are offered at the hospital and therefore combination of alternative treatment and conventional cancer treatment can be a bad combination.
- How much money can and will you spend on the treatment?
Alternative treatment is not covered by the health insurance and therefore the patient have to consider how much they are willing to pay for treatments within the alternative market, maybe also compared to what they can expect to get out of it.
- What is the professional background of the therapist and what professional experience does the therapist have treating cancer patients?
Alternative treatment is a jungle to the patients and they have to be critical towards what are the professional background of the therapist that they choose.

- **Danish Cancer Society Navigator project : To support socially vulnerable cancer patients throughout their course of cancer**

Socially disadvantaged cancer patients experience a problematic and less coordinated cancer journey, even more than other patients do. These patients also find it harder to find the right entrances into the system and get a good dialogue with the healthcare staff.

In Denmark, The Danish Cancer Society over the past five years developed the Navigator Project. Socially vulnerable cancer patients are associated with a voluntary navigator who

supports them throughout the cancer process, from diagnosis and treatment at the hospital to municipal rehabilitation. Navigator's tasks typically include:

- Take part in conversations at the hospital and the municipality
- Help create an overview of the cancer process
- Listen to the patient and give emotional support

An evaluation of the Navigator Project shows that the cancer patients' health competencies and well-being increase significantly during the Navigator course, and these changes remain after completing the Navigator course.

- **Men & Cancer**

When looking at gender and cancer from the man's side, the striking differences in survival are central. The incidence (annual incidence 2011-15) of cancer (excluding "other skin cancer") is 7% higher for men than for women (age-standardized) according to NORDCAN. But the annual mortality age-standardised rate for men is 28 % higher than for women.

Focus was on

- why is the cancer mortality for men four times higher than the difference between gender seen for incidence.
- the relationship between men and health care, health care and men and various gender-based strategies in the patient role.

How results from research can be presented to patients and the population in general

All the cancer societies in the Nordic countries funds cancer research. Cancer research opens for better cancer care and treatment. Research gives hope for people affected by cancer. Further the possibility to fund cancer research is an important factor for many who support the cancer societies.

To inform patients and the population in general, and to "report" back to people, that have supported cancer societies, it is important that national cancer societies can present results/outcome from research in an understandable way. However, it is acknowledged that results from cancer research can be difficult to communicate because of the complexity of the research.

A working group chaired by the Norwegian cancer Society has been established to prepare a workshop in 2019 on how to present results from research to patients and the population in general.

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 3 new strategic projects in 2018:

- Cancer Pathways,
- Cost and outcomes of cancer in the Nordic countries
- Nordic Summer School in Cancer Epidemiology

New confirmed financial support 2018

Nordic Research on Cancer Pathways	2018 - 2019	70.000 euros
Cost and outcomes of cancer in the Nordic countries	2019 -2020	118.500 euros
Nordic Summer School in Cancer Epidemiology	2019 -2020	92.300 euros
Total confirmed support		280.800 euros

Nordic Research on Cancer Pathways

A multidisciplinary research network has been set up with support from Nordic Cancer Union and Confederation of Regional Cancer Centres in Sweden. The aim is to inspire to and conduct multidisciplinary and cross-country comparative research of the function, impacts and effectiveness of the standardized cancer pathways that have been developed in Denmark, Norway and Sweden and soon in Finland as well. Examples of research could be:

- What characterizes patients undergoing/not undergoing the pathways and does it impact on patient reported experiences and outcomes?
- How did the implementation of standardized cancer pathways differ across countries?
- How to learn more about alarm symptoms and early detection of cancer?

NCU believe it is possible to learn from each other better via comparative research. The group shall support and coordinate Nordic research projects, set up a home page and meet regularly in the total group and specific groups.

Contact: Helena Brändström: helena.brandstrom@skl.sk

Cost and outcomes of cancer in the Nordic countries

The aim of the study is to provide insight into cancer costs and drivers, which affect the costs in the Nordic countries and combine them with currently available outcome measures (NORD-CAN). To do so clearly defined harmonized cost indicators across the Nordic countries are needed. As a secondary objective of the project, uniform and comparable data specifications developed between the countries will enable easier updating of the comparisons in the future. The study will also map the Nordic situation on patient-relevant outcome measures (PROM) in each country and relate these to both health economy and outcomes of cancer care. The study will identify key development issues in the data, which is collected, and the contents of national registries, especially regarding outcome measures.

Contact: Sakari Karjalainen, secretary general, Cancer Society of Finland sakari.karjalainen@cancer.fi

Nordic Summer School in Cancer Epidemiology

With NCU support the ANCR have hosted a summer school every second year since 1991, aimed at students in epidemiology (Medicine, Statistics, Biology, Nursing, Public health etc.). Gradually the course has been opened for PhD students and newcomers to epidemiological and clinical research. The course has been instrumental in attracting new researchers to cancer statistics and epidemiology where the Nordic Countries and the NCU can contribute importantly to global cancer control.

The aim of the course is to increase research competence and the utilisation of population-based databases in cancer (cancer registries etc.) for new knowledge, benchmarking and follow-up and thus policy development and evidence base for cancer societies.

The collaboration between the Nordic Cancer Registries and the NCU on training is unique as a tool to recruit and stimulate the next generations to cancer research, to enhance and support the networking within the Nordic countries in cancer research and epidemiology. The most prominent area where Nordic countries can contribute as no one else is in the field of population-based research due to the wealth of registries. The Summer School not only stimulates future use but also presents the use of registries - and secures that information from a 25 million population - is used to improve cancer care and prevention - not only for Nordic people but also worldwide by producing solid unambiguous results compared to many other settings.

Nordic Summer School in Cancer Epidemiology 2019 - 2020

During 2 weeks of intensive basic training, the course introduces theories of research and cancer epidemiology, population based as well as clinical, and provides a network between students and competent researchers and peers in the field. Each student is provided a tutor from a cancer registry research group and a research project to complete during the 2 month' practical work period. Half a year after the theoretical part students and tutors meet to present and discuss results. Hence, the course is comprehensive from idea, theory, and practical to reporting and peer review.

Many previous students are now active in research - most in public health, registries and clinics but also laboratory research has received researchers with good skills in epidemiology, strengthening translational research. Impact of this activity is long term for students, but also short-term benefits for the institutes having projects carried out during the 1 course period. The course is unique in its set-up mixing theory and work on real data of which most end up in peer reviewed publications.

Any development in cancer prevention, treatment and care requires competent researchers. Competence and availability of researchers in the cancer field requires investments with targeted training specific to cancer. The Nordic Summer School in cancer epidemiology is such an investment and has been rated very important by the Cancer Societies' advisory research committee. The need to attract the best brains to cancer research and population based cancer research in order to meet the goal of reducing the burden of cancer and cancer deaths in the future is obvious. The course includes education on the unique possibilities related to effective use of all Nordic register-based data. This type of education is not available in any of the international courses of epidemiology, neither in the handbooks, nor in university settings.

Contact: Klaus Kaae Andersen, Head of statistics, Statistics and pharmaco epidemiology, Danish Cancer Society Research Center, klaus@cancer.dk

Table 1– Overview Strategic Project Grants 2015 - 2020

Strategic projects overview

Project overview - Agreed by the Board of NCU, in May 2017 - changed in October 2018.

All amounts in EURO

	Notes	Total support	Planned in 2015	Planned in 2016	Planned in 2017	Planned in 2018	Planned in 2019	Planned in 2020
Confirmed financial support								
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	
Total confirmed support		449.600	64.400	101.900	131.650	116.650	35.000	0
		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 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			
.....								

Nordic Summer School in Cancer Epidemiology	4	92.300			92.300	-18.300		
Pakkeforløb i de nordiske lande	5	70.000				35.000		
Total actual payments		449.600	13.227	14.137	257.623	66.700	0	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

		Total support	Planned in 2015	Planned in 2016	Planned in 2017	Planned in 2018	Planned in 2019	Planned in 2020
Unpaid confirmed financial support	Notes							
Secretariat for Nordic NECT	1	148.000						
UICC/IARC summer school	2	32.800						
NORDCAN	3	106.500				35.500		
Nordic Summer School in Cancer Epidemiology	4	92.300						
Pakkeforløb i de nordiske lande	5	70.000					35.000	
Nordic Summer School in Cancer Epidemiology 2019	6	92.300					77.300	15.000
Cancer omkostninger i de nordiske lande	7	118.800					59.250	59.250
Total confirmed support		660.700	0	0	0	35.500	171.550	74.250

NCU Scientific Committee recommendations 2018

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, Phd, Professor of medical biochemistry, University of Turku

Sweden:

Klas Kärre, Phd, 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:

Eirikur 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 24 October 2018. The Nordic Cancer Union (NCU) received 30 grant applications in 2018.

The committee recommends that 16 projects are granted by the NCU Board. A list of the projects for which funding is recommended is presented on pages 3 - 4. 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 2015 to 2018.

Table 2: Number of applications and level of funding granted

	2018	2017	2016	2015
Number of applications received	30	42	34	41
Number and ratio (%) of applications funded	16 (53 %)	19 (45 %)	16 (47 %)	16 (39%)
Total amount of funding applied for (€)	4,432,625	4,042,386	3,221,733	3,203,311
Total funding granted (€)	750,000	750,000	750,000	750,000
Ratio of funding received to amount applied for – successful applications (%)	-	40 %	48 %	62 %
Ratio of funding received to amount applied for (%)	17 %			

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 is low compared to previous years (2018:30, 2017:42, 2016:34, 2015:41, 2014:35, 2013:42, 2012:30, 2011:41). In general, the committee found the quality of the applications to be good.

NCU received applications for 10 on-going and 20 new projects. SC recommends 10 on-going and 6 new projects for funding in 2018.

Location of principal investigator

Figure 1 shows the number of applications from each of the Nordic countries in 2018 (determined by the workplace location of the principal investigator). Figure 2 shows the total number

of grant applications received by the NCU from 2015 to 2018. Figure 3 shows each location's share of the recommended applications (determined by the workplace location of the principal investigator).

Figure 1: Number of applications (recommended and not recommended) by location in 2018

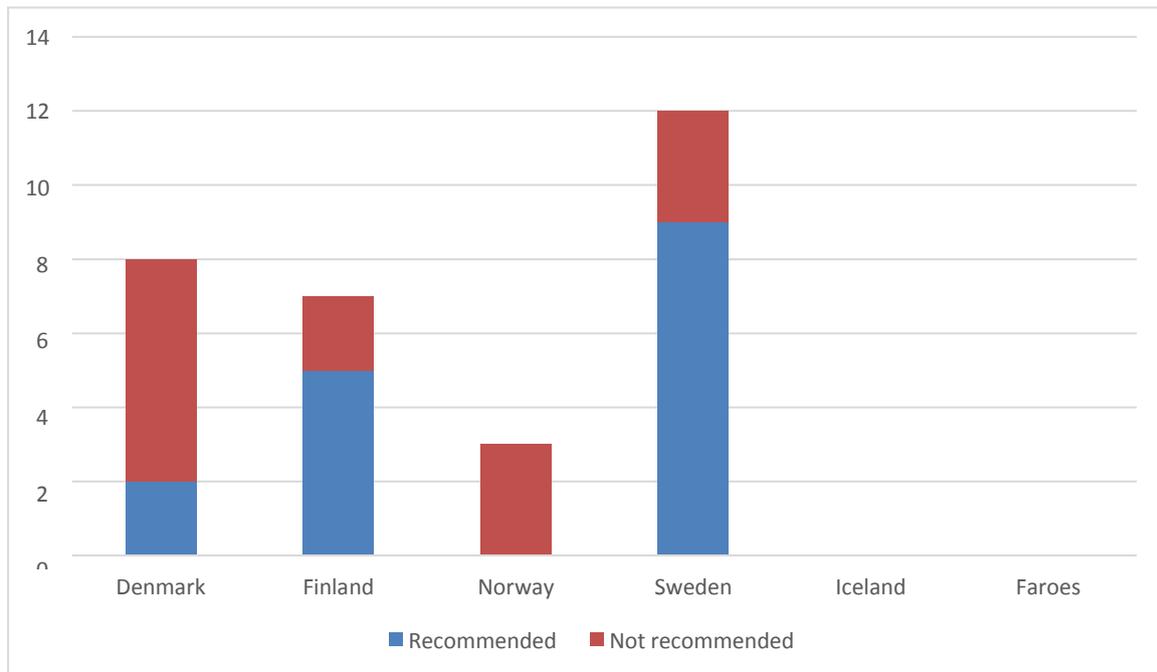
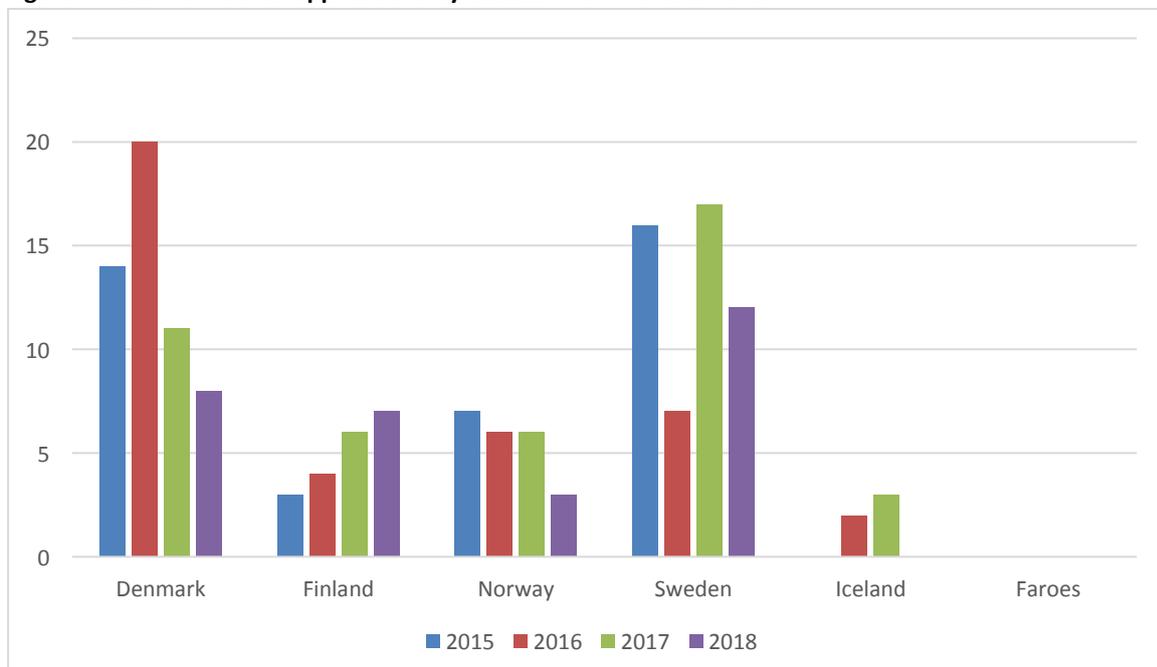


Figure 2: Total number of applications by location from 2015 to 2018



Projects recommended to the NCU Board for funding in 2018

Table 3: Projects recommended to the NCU Board for funding in 2018

Principal investigator	Project title	Project workplace (principal investigator)	Applied amount	Recommended amount
Ahti Anttila	Comparing cervical cancer screening in the Nordic countries: Transition from cytology to HPV testing	Finnish Cancer Registry/ Cancer Society of Finland	50.000	40.000
Anders Pærregaard	The incidence of cancer and mortality in paediatric onset inflammatory bowel disease - A population-based multicentre study from Denmark and Finland	Copenhagen University	34.500	30.000
Asgeir Store Jakola	A novel use of an old drug to treat brain tumors	Department of Neurosurgery, Sahlgrenska University Hospital	65.000	50.000
Björn Nilsson	Genetic predisposition for multiple myeloma: clinical impact of recently identified risk variants	Lund University	90.416	50.000
Eero Pukkala	New wave of joint Nordic studies on work and cancer	Finnish Cancer Registry	202.000	50.000
Håkan Jons-son	Estimation of Overdiagnosis in Breast Cancer Screening	Umeå University	1.098.261	50.000
Jana de Boniface	Survival and axillary recurrence after sentinel node-positive breast cancer without axillary lymph node dissection: the randomized controlled SEN-OMAC trial.	Karolinska Institutet	546.853	65.000
Jesper Lagergren	Antireflux surgery and cancer risk in the Nordic Anti-reflux Surgery Cohort (NordASCo)	Karolinska Institutet	62.487	50.000
Jiong Li	Maternal diseases during pregnancy and childhood leukemia in the offspring: a cohort study in 8 million children in five Nordic countries	Department of Clinical Epidemiology, Aarhus University	75.000	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	51.700	30.000
Kim Sverker Pettersson	NANOPARTICLE AIDED GLYCOVARIANT BIOMARKERS FOR THE EARLY DETECTION OF EPITHELIAL OVARIAN CANCER (2nd year application)	University of Turku	60.000	60.000
Mats Jerkeman	Mantle cell lymphoma - a comprehensive Nordic initiative to improve patient outcome	Lund University	187.950	50.000
Olof Akre	SPCG-15: SURGERY VERSUS RADIOTHERAPY FOR LOCALLY ADVANCED PROSTATE CANCER: A RANDOMIZED CLINICAL TRIAL	Karolinska University Hospital	50.000	50.000
Satu Mustjoki	Immunological monitoring of therapy response in chronic myeloid leukemia by the Nordic CML study group (NCMLSG)	University of Helsinki	100.000	65.000
Sirpa Leppä	Precision medicine in aggressive B-cell lymphomas	Helsinki University Hospital Comprehensive Cancer Centre/University of Helsinki with Nordic Lymphoma Group Large B-Cell working group	100.000	30.000
Ulf Gunnarsson	MSI in sporadic colorectal cancer: register data and tissue analyses regarding cancer in other organs, clinical presentation and immune response.	Umeå University	382.000	40.000

The recommendations from the Scientific Committee was approved by the NCU Board 24 October 2018.

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