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NCU strategy for the years 2015-2018

The Nordic Cancer Union (NCU), established in 1949, is a collaborative body for the cancer societies in the Nordic countries. The NCU is comprised of six organizations: Danish Cancer Society, Cancer Society of Finland, Icelandic Cancer Society, Norwegian Cancer Society, Swedish Cancer Society and Faroese Cancer Society. The aim of the NCU is collaboration to improve knowledge and understanding of cancer diseases, their effective prevention, treatment and rehabilitation. The principal role of the NCU is to provide a forum for the national cancer societies in the Nordic countries to meet and exchange relevant information about national and international activities, best practices and future plans.

The members of the Nordic Cancer Union have a common vision: "more life without cancer and the best possible life for those with cancer and their families." The challenge of today is an increasing number of elderly people and their risk of contracting cancer, combined with the gap in knowledge of important risk factors and population behaviour. The Cancer Societies cannot solve this problem, but they can create a basis for well-founded advocacy through the activities they support, and thus point to societal changes related to health and health care. Advocacy is thus a major pillar in the NCU strategy alongside collaboration and synergy in research, prevention and care.

In addition to providing a forum for information sharing, the NCU funds Nordic cancer research in accordance with the NCU Research Strategy. The NCU has also taken the initiative in common Nordic projects carried out by national cancer societies and different strategic projects. The NCU strategy is formed taking account of the similarities between the Nordic populations, totalling more than 25 million people. The Nordic populations live in relatively affluent and public-service-based environments with effective high-quality monitoring. Using this situation intelligently can significantly contribute to the global fight against cancer.

This strategy is a reflection of the shared priorities of the national cancer societies in the Nordic countries. It is grounded in the NCU statutes, the NCU strategy for the years 2010-15, the NCU research strategy 2014 and the NCU proposal to the Nordic Council of Ministers on future collaboration. The strategy will provide guidance for the NCU in establishing joint projects and allocation of NCU funds, currently one million euro each year.

There are five main points in this strategy, for each of which a number of implementation approaches are described. Targets will be developed as needed during the three-year period to which the strategy applies.

The main points of the 2015-18 strategy are:

1. Reduce risk of cancer; implement existing knowledge with the aim of preventing up to 40% of cancer diseases.
2. Improve life with cancer; optimal diagnosis and treatment according to high international standards including rehabilitation and palliative care as necessary.
3. Support joint and comparable monitoring of cancer and outcome as a basis for equal and best possible care, and clinical research.
4. Nordic countries as leaders in excellent collaborative cancer research, both basic and clinical, utilising the special conditions related to well-monitored populations and national biorepositories.
5. Joint up-to-date information on cancer to the public, and common Nordic advocacy to influence public policy in the Nordic countries and globally.

Statutes of the Nordic Cancer Union

§ 1 Preamble

The Nordic Cancer Union (NCU) is a collaborative body for co-operation on relevant strategic issues, exchange of experiences and inspiration of new initiatives for the Danish Cancer Society, the Faroe Cancer Society, the Cancer Society of Finland, the Icelandic Cancer Society, the Norwegian Cancer Society and the Swedish Cancer Society.

The overall strategies and priorities for NCU are stipulated for three-year periods by the NCU Board and should be valid during a member countries chairmanship.

§ 2 Aim and strategy

The overall goal for the NCU is to ensure best treatment for cancer patient, and implementation of effective cancer preventing initiatives in the Nordic countries

- Provision of a forum for exchange of knowledge and discussion amongst the Nordic cancer societies.
- Collaboration to improve knowledge and understanding of cancer diseases, effective prevention and health promotion, results of cancer treatment and rehabilitation; and to enhance effective application in the Nordic area.
- Funding Nordic research and strategic projects of highest possible standards and of relevance to the member organizations within the field of cancer according to strategies on research and strategic projects decided by the NCU Board at any given time.

§ 3. Registered office

The Board makes decisions regarding the location of the registered office site.

§ 4. The NCU Board

The NCU is governed by a Board comprising representatives of each of the member organizations of NCU.

Each organization may appoint up to three representatives for participation in board meetings – one of these at CEO and/or chairman level. Specialists/staff members of the member organizations may participate in board meetings and/or represent the members. The Board is responsible for informing the chairmen of meetings, when a need for their presence arises.

Voting in the Board is on the basis of one organization one vote. Decisions of the Board are taken by a simple majority of the Board members present. In the event of a tied vote, the NCU chairman has a second, casting vote.

4.1 The Board makes decisions congruent with the aim and strategies of the NCU concerning

- Grants for strategic projects.
- Grants for scientific projects after recommendations from the Scientific Committee.
- Other issues, e.g. with joint statements.

4.2. The Board approves

- Every three years the chairmanship for the coming three-year period.
- Every three years the strategic plan for the coming three-year period.
- Change of statutes.
- Meeting plan for at least the coming two meetings.

4.3. The Board may decide

- To establish committees and appoint committee members.
- To hold workshops in connection with board meetings and decide main themes for such workshops e.g. regarding discussions of actual, principled cancer relevant issues, long-term strategies and evaluation of activities.

4.4 The Board has 3–4 annual meetings. Main topics of the meetings include:

- Exchanges of experiences, decisions on strategic projects when needed.
- Approval of annual budget including allocation between strategic and scientific projects.
- Report from the scientific committee and progress reports from strategic projects.
- Approval of accounts and annual report for previous year.

4.5. The minutes of the Board are adopted electronically and formally signed at the following meeting by a representative from each member organization participating in the meeting.

§ 5 Chairmanship and Secretariat

The chairmanship is held alternately by the members for a three-year period taking effect from the start of a calendar year.

The chairmanship of the NCU is responsible for the Union's secretariat function during the mandate period in relation to general matters and the scientific committee. The responsibility for the NCU secretariats function may be transferred to another member country than that of the NCU chairman by a specific agreement, which has to be accepted by the majority member countries. Similarly, the responsibility of the

secretariat of advisory committees, including the scientific committee, may by a specific agreement for a period of time be transferred to another member organisation than that of the NCU chairman.

NCU contributes to the costs of the secretariats as decided by the Board.

§ 6 Scientific Committee

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.

The tasks of the Scientific Committee are:

- To assess scientific grant applications and secure that they are aligned with the NCU research strategy and of high scientific quality, and formulate recommendations regarding the applications to the NCU Board for the Board's decisions on grants.
- Can be asked to give consultation concerning strategic project regarding research to the Board for its decisions on grants.
- To evaluate funded research and follow-up on the application of the results in the Nordic countries.
- The chairman of the Scientific Committee is invited to an annual meeting with the Board.

§ 7 Finances

The NCU's funds are deposited and managed in a separate account by the cancer society which receives the funds that are placed at the disposal of the Union.

The annual budget, cost allocation between the members and balancing of the accounts are approved by the Board. The accounts are formally revised by a certified public accountant and informally by the previous chairmanship, prior to a presentation to the Board.

The NCU may receive grants and donations, from which it may pay out grants and provide support for strategic projects.

§ 8 Signatories

The chairman of NCU or two other Board members authorised by the Board may sign jointly on behalf of the NCU.

§ 9 Changes of statutes and dissolution of the Nordic Cancer Union

Any member of the NCU may propose changes to the statutes and these shall be sent to the Secretariat of the NCU and communicated by the Secretariat to all NCU members not later than two months prior to the meeting for the Board.

The chairman or two members of NCU may call for an extra-ordinary meeting of the Board with at least two months' notice stating the agenda.

The quorum of attendance required for changes of statutes or dissolution is at least three quarters of full members present or voting by proxy.

In the event of the dissolution of NCU, any financial assets owned by the NCU shall be distributed among its members in proportion to the apportioning index.

Statutes approved by the NCU Board on May 30th 2016.

Nordic Cancer Union – Summary of survey autumn 2017

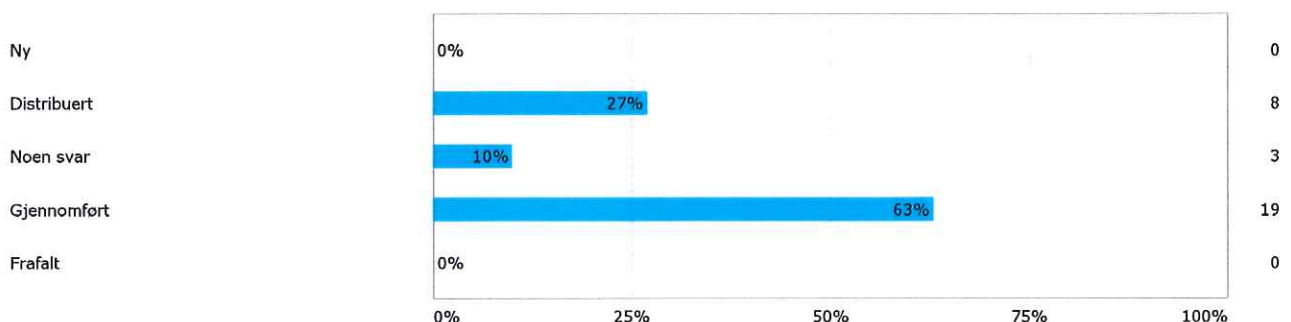
Background

There is a need to increase the knowledge about the “effect” of NCU funded research. On this background the NCU Research Administration at the Norwegian Cancer Society sent out a brief survey on August 28. to 30 principal investigators that had received funding in 2012, 2013, 2014 and 2015. The purpose of the survey was to gain more information about the impact of NCU research that can be used as a starting point for further enquiries. It is worth mentioning that reports from each project can be obtained on the NCU web page.

In our survey we did not include the projects that received funding in 2016 as many had just started with their research. Firstly, the respondents received a one-week deadline. After a second round, we received 19 complete answers (63 %) on which to base our summary (11 surveys were invalid).

This is not a large number of respondents, but relative to the number of projects that have received NCU funding and that the same applicant often has applied for renewals, the 19 answers may be seen as a basis for further analysis.

Tab 1. Number of respondents

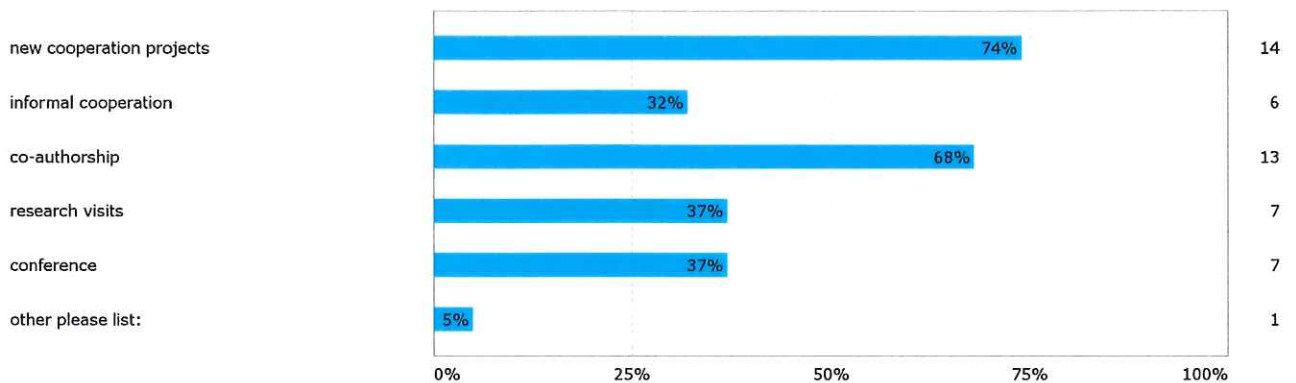


Of all the answers sent in, eight were from research institutions in Sweden and Denmark, three from Finland, two from Norway and one from Iceland. See also attachment 1: Overview of NCU projects 2012 – 2015, name and title of project.

Future co-operation

As the first question we asked the respondent if the Nordic collaboration extended beyond the financing period, and in what form. Of the 19 respondents only four did not indicate any post project cooperation.

Tab 2. Nature of cooperation after NCU-funding period.

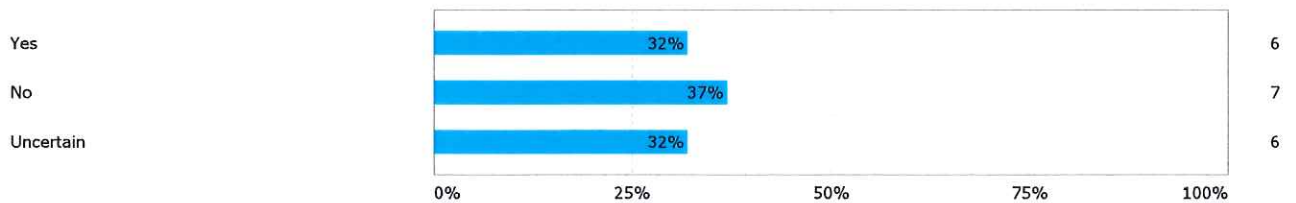


Asked what type of collaboration 14 (74%) of 19 respondents indicated that NCU funded projects had led to new cooperation projects. Thirteen indicated that their cooperation had led to co-authorship. Six answered it had led to informal cooperation. Seven answered research visits and conference.

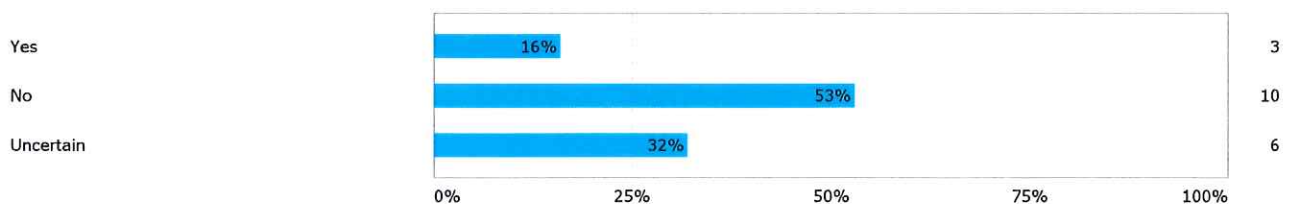
Impact

We asked the respondents if it was possible to report any form of impact of their project. Six respondents answered that the project brought new guidelines for prognosis for practitioners/patients, seven respondents said no, and six were uncertain. When asked whether the project had led to any new treatment, the majority said "no" (ten respondents) and only three said "yes". Six were "uncertain":

Tab 3. Did the project bring any new guidelines for prognosis for practitioners/patients?



Tab 4. Did the project bring any new treatment?



It was also possible for the respondents to give an open answer regarding other aspects that the various projects have brought about. Following answers are listed here:

- About 70 publications, 2 courses, 50 invited lectures, TV programs,
- New diagnostic
- Deeper biological understanding
- Improved understanding of prognosis
- The project provided biological evidence of the importance of immune system in treatment discontinuation, which is already now taken into account when planning new clinical trials and treatment protocols
- Improved knowledge in cancer aetiology

- *Development in Research methodology to obtain more valid estimates*
- *Possible harmonization of handling of stem cell donors between centres*
- *Project is still ongoing*
- *Knowledge about long term effects of cancer and cancer treatment*
- *Personalized diagnostics*
- *Possibilities of monitoring stage distribution and stage-specific and time trends*
- *Personalised/Precision Medicine implementation in haematological cancer*

A positive consequence of the NCU funding is that 15 respondents out of 19 answered that the project had led to publication in a peer-reviewed journal. (Four answered no).

We also asked the respondents to list the publications (See attachment 2).

The NCU scheme – user experience

We asked the respondents to evaluate their experience with the overall process of the NCU scheme. We are pleased that 14 of them answered “very good” and three “good” (2 answered “satisfactory”). We also welcomed the respondents to indicate improvements. The suggestions are listed here:

- *“The most important negative aspect is that a stable cooperative group like NMDSG only can apply for 12 months. It is unnecessary work both for us and you. Good projects should be valid for 3 years.”*
- *“Funding of strong research projects that continue for more than 3 years would greatly increase the weight and visibility of NCU in global cancer control perspective.”*
- *“The IT platform needs an upgrade”*
- *“NCU is only a part of my project expenses, I have to apply funds from other sources to cover salary for my postdoc researchers.”*

Co-funding

Of the 19 respondents, 13 indicated that they had received funding for the project from other sources. Most of the respondents indicated their own country as the country where they applied for other funding. See the listed sources here:

Sweden:

- The Swedish Cancer Society (five respondents)
- Swedish Research Council (three respondents)
- Stockholms Cancerförening (one respondent)
- Childhood Cancer Foundation (one respondent)
- The Regional Research Council in the Uppsala-Örebro region (one respondent)

Denmark:

- Danish Cancer Society (two respondents)
- Childhood Cancer Foundation (one respondent)
- The Otto Christensen Foundation (one respondent)
- The University Hospital Rigshospitalet (one respondent)
- The Novo Nordic Foundation (one respondent)
- Danish Research Council (one respondent)
- Danielsen Fonden and Willumsen Fonden (one respondent)
- Nordiska Ministerrådet (one respondent)

EU (one respondent)

Norway:

- Norwegian Cancer Society (one respondent)

Finland:

- Sigrid Juselius Foundation (one respondent)

Forms of schemes – Nordic cancer research

As a last question, we asked the respondents to describe any other reflections related to the improvement of the finance schemes, e.g. other forms of financing, clearer criteria, better arenas for cooperation. Here are the answers we received:

- “NCU has decreased its project funding during the last years. It is no longer possible to manage without other funding”
- “Part of the finance is covered by basis in each of the cancer registries.”
- “New clinical trials to validate Precision Medicine by clinical end points is needed.”
- “I understand that it may be difficult for NCU to finance 100% of project expenses, but it is great that NCU can contribute significantly to some of the ongoing projects. I think the current schemes are great.”

Concluding remarks

We are well aware about the limitations of this survey study presented here, but we still think it gives some insights in the impact of NCU research funding. We are very happy to see that a large share of the respondents reported that their Nordic collaboration had continued beyond the period financed by NCU. This indicates that NCU funding can be an important factor for Nordic research.

This small study also gives ideas for further investigations of the effects of NCU research. It would for example be possible to initiate a bibliometric analysis based on the reported publication (attachment 2). It would also be possible to make a more qualitative approach interviewing some of the partners listed in these projects.

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Attachment 1: Overview of NCU projects 2012 – 2015

| Applicant year 2012 | Title | Country of research institution and PI | Answered the survey | A few answers | No answer |
|----------------------------|---|---|----------------------------|----------------------|------------------|
| Hellström Lindberg, Eva | Nordic MDS Group (NMDSG) Clinical Trial program and new biobank and molecular platform to improve outcome for patients with MDS | Sweden | X | | |
| Lynge, Elsebeth | Mammography: from a pragmatic to an individualised screening schedule | Denmark | | X | |
| Jönsson, Göran | Molecular epidemiology of familial ocular and cutaneous malignant melanoma | Sweden | X | | |
| Johnsen, Hans Erik | Prognostic Classification and Prediction of Clinical Resistance in Multiple Myeloma - EMN-02 / NMSG19/10 | Denmark | X | | |
| Li, Jiong | Medication during pregnancy and cancer risk in offspring: a cohort study in 2 million children in Denmark, Sweden, and Finland. | Denmark | X | | |
| Grotmol, Tom | Norwegian-Swedish genome wide association study of testicular cancer with special focus on coding regions | Norway | | | X |
| Pukkala, Eero | Work and cancer: in-depth studies initiated by the NOCCA project | Finland | X | | |
| Schmiegelow, Kjeld | EXPLORING AND IMPROVING THIOPURINE/METHOTREXATE MAINTENANCE THERAPY OF ACUTE LYMPHOBLASTIC LEUKEMIA | Denmark | X | | |
| Anne-Lise Børresen-Dale | HER2 positive breast cancers and drug response; a Finnish-Norwegian collaboration | Norway | | | X |

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| Tammela, Teuvo | Prostate cancer screening in Finland & Sweden – Why is the efficacy so different? | Finland | | | |
| Wiklund, Fredrik | Genetic epidemiology of prostate cancer prognosis | Sweden | | | |
| Barkardottir, Rosa Bjork | Molecular Epidemiology of Familial Breast Cancer in the Nordic Countries: Search for Novel Genes in High-Risk Families | Iceland | | X | |
| Mustjoki, Satu | The nordic CML study group: Immunological evaluation of factors related to the successful therapy discontinuation | Finland | X | | |
| Applicant year 2013 | Title | | | | |
| Lagergren, Jesper | Influence of obesity surgery on cancer risk in a Nordic population-based cohort study | Sweden | X | | |
| Dillner, Joakim | Optimisation of HPV-based cancer control strategies | Sweden | | | X |
| Peltomäki, Päivi | Search for novel high-penetrance susceptibility genes for familial colorectal cancer from Finnish and Danish cohorts | Finland | X | | |
| Bjørge, Tone | Pregnancy characteristics and maternal cancer: A joint Nordic study | Norway | | | X |
| Grotmol, Tom | Norwegian-Swedish genome wide association study of testicular cancer with special focus on coding regions | Norway | | | X |
| Mustjoki, Satu | The nordic CML study group: Immunological evaluation of factors related to the successful therapy discontinuation | Finland | X | | |
| Johnsen, Hans Erik | Prognostic Classification and Prediction of Clinical Resistance in Multiple Myeloma - EMN-02 / NMSG 19/10 | Denmark | X | | |
| Nordin, Karin | PhysCan-Physical training and cancer | Sweden | X | | |
| Barkardottir, Rosa Bjork | Molecular Epidemiology of Familial Breast Cancer in the Nordic Countries | Iceland | | X | |

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|----------------------------|---|---------|---|--|---|
| Hellström Lindberg, Eva | Nordic MDS Group (NMDSG) Clinical Trial program and new biobank and molecular platform to improve outcome for patients with MDS | Sweden | X | | |
| Dickman, Paul | Nordic cancer survival query system: A web-based platform for presenting estimates of cancer patient survival to patients | Sweden | X | | |
| Schmiegelow, Kjeld | EXPLORING AND IMPROVING THIOPURINE/METHOTREXATE MAINTENANCE THERAPY OF ACUTE LYMPHOBLASTIC LEUKEMIA | Denmark | X | | |
| Pukkala, Eero | Work and cancer: in-depth studies initiated by the NOCCA project | Finland | X | | |
| Tammela, Teuvo | PROSTATE CANCER SCREENING IN FINLAND AND SWEDEN – WHY IS THE EFFICACY SO DIFFERENT? | Finland | | | X |
| Jönsson, Göran | Molecular epidemiology of familial ocular and cutaneous malignant melanoma; a Swedish-Danish collaboration | Sweden | X | | |
| Wiklund, Fredrik | Genetic epidemiology of prostate cancer prognosis | Sweden | X | | |
| Li, Jiong | Medication during pregnancy and cancer risk in offspring: a cohort study in 2 million children in Denmark, Sweden, and Finland | Denmark | X | | |
| Applicant year 2014 | Title | | | | |
| Peltomäki, Päivi | Search for novel high-penetrance susceptibility genes for familial cancer from Finnish and Danish cohorts | Finland | X | | |
| Abildgaard, Niels | Prolonged Bone Protection in Multiple Myeloma - the Magnolia Study. | Denmark | X | | |
| Bjørge, Tone | Pregnancy characteristics and maternal cancer: A joint Nordic study | Norway | | | X |
| Nordin, Karin | Phys-Can. Physical training and cancer | Sweden | X | | |

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|---|---|---------|---|--|---|
| Brown - for the Nordic Lymphoma Group, Peter de Nully | Biomarker-driven, risk-adapted trials in aggressive lymphomas and Hodgkin lymphoma | Denmark | X | | |
| Dillner, Joakim | Optimisation of HPV-based cancer control strategies | Sweden | | | X |
| Lagergren, Jesper | Influence of obesity surgery on cancer risk in a Nordic population-based cohort study | Sweden | X | | |
| Kjærheim, Kristina | Lifestyle and occupational cancer risk - adjusting for alcohol and tobacco | Norway | X | | |
| Mustjoki, Satu | The nordic CML study group: Immunological evaluation of factors related to the successful therapy discontinuation | Finland | X | | |
| Grotmol, Tom | Association between gene variation and the response to chemotherapy for testicular cancer - clinical outcomes and adverse effects | Norway | | | X |
| Hägglund, Hans | Potential hazards for hematopoietic stem cell donors | Sweden | X | | |
| Hellström Lindberg, Eva | Nordic MDS Group (NMDSG) Clinical Trial program and new biobank and molecular platform to improve outcome for patients with MDS | Sweden | X | | |
| Jönsson, Göran | Molecular epidemiology of familial ocular and cutaneous malignant melanoma; a Swedish-Danish collaboration | Sweden | X | | |
| Fuxe, Jonas | Exploring immune cell properties of cancer cells as an early sign of metastasis in Swedish and Finnish breast cancer patients | Sweden | | | X |
| Herrstedt, Jørn | EWOC-1 (Elderly Women Ovarian Cancer) Trial | Denmark | | | X |
| Applicant year 2015 | Title | | | | |
| Lagergren, Jesper | Influence of obesity surgery on cancer risk in a Nordic population-based cohort study | Sweden | X | | |

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|-------------------------|--|---------|---|---|---|
| Abildgaard, Niels | Prolonged Bone Protection in Multiple Myeloma - the Magnolia Study | Denmark | X | | |
| Dillner, Joakim | Optimisation of HPV-based cancer control strategies | Sweden | | | X |
| Kjærheim, Kristina | Lifestyle and occupational cancer risk - adjusting for alcohol and tobacco | Norway | X | | |
| Hägglund, Hans | Potential hazards for hematopoietic stem cell donors | Sweden | X | | |
| Hellström Lindberg, Eva | Nordic Collaborative Clinical Database Initiative and Allogeneic Stem Cell Transplantation Project for Myelodysplastic Syndromes | Sweden | X | | |
| Schmiegelow, Kjeld | CLEAR: Individualized Central nervous system therapy of acute Lymphoblastic leukemia to increase Efficacy And Reduce toxicity | Denmark | X | | |
| Li, Jiong | Maternal diseases during pregnancy and childhood leukemia in the offspring: a cohort study in 8 million children in five Nordic countries | Denmark | X | | |
| Hjalgrim, Henrik | Blood transfusions as a risk factor for malignant lymphoma – fact or fiction? | Denmark | | X | |
| Giwerzman, Aleksander | The impact of testicular cancer and its treatment on the health of the offspring | Sweden | X | | |
| Grønberg, Bjørn H. | A Randomized Phase II Study Comparing Two Schedules of Hyperfractionated Thoracic Radiotherapy in Limited Disease Small-Cell Lung Cancer | Norway | X | | |
| Peltomäki, Päivi | Search for Novel High-Penetrance Susceptibility Genes for Familial Colorectal Cancer from Finnish and Danish Cohorts | Finland | X | | |
| Engholm, Gerda | NORDCAN development; Differences in cancer survival in the Nordic countries: the role of stage at presentation, treatment, comorbidity and education | Denmark | X | | |

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|---|--|---------|---|---|---|
| Lynge, Elsebeth | Impact of screening on cancer incidence trends and age-patterns | Denmark | | X | |
| Brown - for the Nordic Lymphoma Group, Peter de Nully | Clinical trial-based precision medicine in the Nordic countries for patients with aggressive lymphomas | Denmark | X | | |
| Paerregaard, Anders | The incidence of cancer and mortality in Scandinavian paediatric inflammatory bowel disease during a 25 years period (1990-2015) - A population-based multicentre study from four countries | Denmark | | | X |