

Bilagor:

1. Nordic Cancer Union, Financial Statements 2016.
2. Financial budget NCU 2017.
3. Strategic projects overview.
 - Status of the NORDCAN Project.
 - Financial report for NORDCAN secretariat 2016.
 - Scientific literature using NORDCAN, searched in PubMed.
 - Description of the NORDCAN update process.
 - Report from the Secretariat for Nordic Network for Early Cancer Trials (Nordic NECT).
4. NCU-research: change in guidelines – Eligibility of the Principal investigator, 3. February 2017.
5. Applications for NCU strategic funds.
 - Nordic Cancer Meeting in Iceland.
 - NORDSCREEN – Project description and Application letter.
6. Meeting with NordForsk. 8th February 2017.
7. Cancer Prevention and control in the context of an integrated approach. Report by the Secretariat, EB 140/31.
 - Ny cancerresolution för beslut på World Health Assembly. Cancerfonden Sverige.
 - UICC Global Advocacy Report 2016.
8. How do the NCU cancer leagues stimulate interest in cancer research?
9. NCUs cooperation with the Nordic Council and the Nordic Council of Ministers and the Bo Könberg report.
 - Status för rapporten Det framtida nordiska hälsosamarbetet, daterad 17 januari 2017.

Nordic Cancer Union

Financial Statements 2016

Nordic Cancer Union
Skógarhlíð 8
105 Reykjavík

Iceland

Contents

Report on Review of Financial Statements	1
Endorsement and Statement by the Board	2
Income statement	3
Balance sheet	4
Accounting Policies and Explanatory Notes	5

Report on Review of Financial Statements

To the Board of Nordic Cancer Union

We have reviewed the accompanying financial statements of Nordic Cancer Union that comprise the endorsement and statement by the board of directors, statement of financial position as at December 31, 2016, the income statement and a summary of significant accounting policies and other explanatory information.

Board's responsibility

The Board is responsible for the preparation and fair presentation of these financial statements in accordance with general accepted accounting practice and for such internal control as management determines is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditors' responsibility

Our responsibility is to express a conclusion on the accompanying financial statements. We conducted our review in accordance with International Standard on Review Engagements (ISRE) 2400, Engagements to Review Historical Financial Statements. ISRE 2400 requires us to conclude whether anything has come to our attention that causes us to believe that the financial statements, taken as a whole, are not prepared in all material respects in accordance with the applicable financial reporting framework. This Standard also requires us to comply with relevant ethical requirements.

A review of financial statements in accordance with ISRE 2400 is a limited assurance engagement. The practitioner performs procedures, primarily consisting of making inquiries of management and others within the entity, as appropriate, and applying analytical procedures, and evaluates the evidence obtained.

The procedures performed in a review are substantially less than those performed in an audit conducted in accordance with International Standards on Auditing. Accordingly, we do not express an audit opinion on these financial statements.

Conclusion

Based on our review, nothing has come to our attention that causes us to believe that these financial statements do not give a true and fair view of the financial position of Nordic Cancer Union as at December 31, 2016 and its financial performance for the year then ended, in accordance with the general accepted accounting practice.

Reykjavík, 9 February 2017

Ernst & Young ehf.



Ragnvaldur Dofri Pétursson
State Authorized Public Accountant

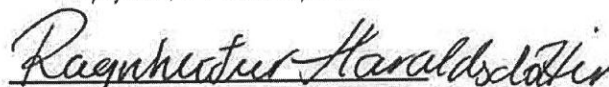
Endorsement and Statement by the Board

The Financial Statements for Nordic Cancer Union are prepared in accordance with general accepted accounting practice.

The board consider the accounting policies used to be appropriate, such that the Financial Statements gives a true and fair view of the Income Statement for the year 2016 and the Balance Sheet at 31 December 2016.

We hereby submit the Financial Statement for the year 2016 to the Board of Nordic Cancer Union for approval.

Reykjavík, 9 February 2017



Ragnheiður Haraldsdóttir

Chairman

Income statement 2016

All amounts in EURO

	Notes	Actual 2016	Budget 2016	Actual 2015
Income				
Income from NCU members		1.077.863	1.077.863	853.147
Interest from bank accounts		306	0	154
Nordic Summer School repaid		2.263	0	0
		<u>1.080.432</u>	<u>1.077.863</u>	<u>853.301</u>
Activity				
Research		750.000	750.000	740.000
Strategic projects		101.900	250.000	61.227
		<u>851.900</u>	<u>1.000.000</u>	<u>801.227</u>
Result before other cost		228.532	77.863	52.074
Other cost				
Secretariat function		65.000	65.000	65.000
Travel cost		10.782	15.000	12.445
Other cost		5.697	12.000	11.445
		<u>81.479</u>	<u>92.000</u>	<u>88.890</u>
Result for the year		<u>147.053</u>	<u>(14.137)</u>	<u>(36.816)</u>

Balance Sheet 31 December 2016

All amounts in EURO

Assets

	Notes	2016	2015
Current Assets			
Short-term receivables		301.802	0
Cash and cash equivalents		853.580	881.577
Total Current Assets		<u>1.155.382</u>	<u>881.577</u>
 Total Assets		 <u><u>1.155.382</u></u>	 <u><u>881.577</u></u>

Equity and Liabilities

Equity

Equity at year beginning	79.137	115.953
Result from operation	147.053	(36.816)
Total equity	<u>226.190</u>	<u>79.137</u>

Liabilities

Current Liabilities

Research	750.000	740.000
Other current liabilities	179.192	62.440
Total Current Liabilities	<u>929.192</u>	<u>802.440</u>
 Total Liabilities	 <u>929.192</u>	 <u>802.440</u>

Total Equity and Liabilities	<u><u>1.155.382</u></u>	<u><u>881.577</u></u>
-------------------------------------	-------------------------	-----------------------

Notes to the Financial Statements 2016

All amounts in EURO

1. General information

The Nordic Cancer Union is a collaborative body for cancer societies in the Nordic countries. The registered office is now at Skógarhlíð 8, 104 Reykjavík, Iceland.

2. Summary of accounting policies

Basis of preparation and statement of compliance

The Financial Statements are prepared in accordance with general accepted accounting practice. The Financial Statements have been prepared on a going concern basis and under the historical cost convention. The Financial Statements are presented in EURO, except when otherwise indicated.

Use of estimates and judgements

The preparation of the Financial Statements requires management to make judgements, estimates and assumptions that affect the reported amounts of revenues, expenses, assets and liabilities, and the disclosure of contingent liabilities, at the end of the reporting period. Use of available information and application of judgement are inherent in the formation of estimates. Actual results in the future could differ from such estimates and the differences may be material to the Interim Financial Statements.

Foreign currency translation

Foreign currency transactions

Transactions in foreign currencies are initially recorded at the exchange rate ruling at the date of the transaction. Monetary assets and liabilities denominated in foreign currencies are retranslated at the exchange rate ruling at the balance sheet date. Gains and losses resulting from the translation of foreign currency transactions are taken to the income statement.

Accounts receivables

Accounts receivables are initially recognised at the transaction price. They are subsequently measured at amortised cost using the effective interest method, less provision for impairment. A provision for impairment of trade receivables is established when there is objective evidence that the association will not be able to collect all amounts due according to the original terms of the receivables. The directors assessment is that no provision is needed at year end.

Cash and cash equivalents

Cash and cash equivalents includes cash on hand, demand deposits and other short-term highly liquid investments with original maturities of three months or less. Bank overdrafts, if any are shown within borrowings in current liabilities on the balance sheet.

Notes to the Financial Statements 2016

All amounts in EURO

Trade payables and other payables

Trade payables and other payables are recognised initially at the transaction price or fair value. These financial liabilities are normally non-interest bearing. Trade payables are normally settled within 2 months, and other payables within 12 months.

Income

Income from NCU members is contribution from NCU members.

Interest income on bank accounts is recognised when earned.

3. Equity

Changes in equity are specified as follows:

	Retained earnings	Total
Equity at 1/1	79.137	79.137
Profit (loss)	147.053	147.053
Equity at 31/12	226.190	226.190

Financial budget NCU 2017

Proposal - Stockholm 17 February 2017, All amounts in EURO

		Proposal 2017	Actual 2016
Income	Notes		
Income NCU members	1	918.810	1.077.863
Total income		918.810	1.077.863
 Area of activity			
Research		750.000	750.000
Strategic projects	2	250.000	101.900
Secretariat function		65.000	65.000
Travel cost		15.000	10.782
Other cost		12.000	5.697
Interest income and repaid cost		-	2.569
Total expenses		1.080.000	930.810
 Net income profit/ - loss	3	- 161.190	147.053
Notes:			
1. Income allocation between the members			
Denmark	28,00%	257.267	301.802
Finland	15,00%	137.822	161.679
Iceland	1,00%	9.188	10.779
Norway	27,80%	255.428	299.645
Sweden	28,00%	257.267	301.802
Faroe Islands	0,20%	1.838	2.156
	100,00%	918.810	1.077.863
 2. Confirmed financial support			
Secretariat for Nordic NECT		50.000	50.000
IARC summer school		16.400	16.400
NORDCAN		35.500	35.500
Nordic Summer School in Cancer Epidemiology		46.150	-
		148.050	101.900
 3. Indirect activities			
Equity at year end		226.190	79.137
Reservation for operation of secretariat function		- 65.000	- 65.000
		161.190	14.137

Strategic projects overview

Project overview - Stockholm 17 February 2017, All amounts in EURO

Confirmed financial support	Notes	Total	Planned in	Planned in	Planned in	Planned in	Planned in
		support	2015	2016	2017	2018	2019
Secretariat for Nordic NECT	1	148,000	48,000	50,000	50,000		
UICC/IARC summer school	2	49,200	16,400	16,400	16,400		
NORDCAN	3	106,500		35,500	35,500	35,500	
Nordic Summer School in Cancer Epidemiology	4	92,300			46,150	46,150	
Total confirmed support		396,000	64,400	101,900	148,050	81,650	0

Actual payments		2015	2016	2017	2018	2019
Secretariat for Nordic NECT	1	148,000				
UICC/IARC summer school	2	49,200	13,227			
NORDCAN	3			71,000		
Nordic Summer School in Cancer Epidemiology	4			92,300		
Total actual payments		197,200	13,227	0	163,300	0

Notes:

1. Confirmed on a Board Meeting in Helsingör in September 2015
2. Confirmed on a Board Meeting in Reykjavik 22 May 2015
3. Confirmed on a Board Meeting in Oslo 19 February 2016
4. Confirmed on a Board Meeting in Copenhagen 25 November 2016

Unpaid confirmed financial support	Notes	Total	Planned in	Planned in	Planned in	Planned in	Planned in
		support	2015	2016	2017	2018	2019
Secretariat for Nordic NECT	1	148,000	48,000	50,000	50,000		
UICC/IARC summer school	2	49,200		16,400	16,400		
NORDCAN	3	106,500				35,500	
Nordic Summer School in Cancer Epidemiology	4	92,300					
Total confirmed support		396,000	48,000	66,400	66,400	35,500	0

Gerda Engholm
 NORDCAN secretariat
 Dept. Documentation & Quality
 Danish Cancer Society
 8 February 2017

Status of the NORDCAN Project

Report for the year 2016.

NORDCAN

In July 2016 NORDCAN was updated to version 7.3 with 2014 data for all countries except mortality for Faroe Islands. The reference is:

Engholm G, Ferlay J, Christensen N, Kejs AMT, Hertzum-Larsen R, Johannesen TB, Khan S, Leinonen MK, Ólafsdóttir E, Petersen T, Schmidt LKH, Trykker H, Storm HH. NORDCAN: Cancer Incidence, Mortality, Prevalence and Survival in the Nordic Countries, Version 7.3 (08.07.2016). Association of the Nordic Cancer Registries. Danish Cancer Society.

Two meetings were held in the NORDCAN group at Danish Cancer Society on 6-7 April and 25-26 October 2016.

The NORDCAN database (Version 7.3, 07.2016)

Data availability				
Country	Incidence	Mortality	Prevalence	Survival
Nordic countries	1960-2014	1953-2014	1980-2014	-
Denmark, national	1943-2014	1951-2014	1963-2014	1965-2014
Denmark, regional	1971-2014	1971-2014	1991-2014	-
Faroe Islands	1960-2014	1983-2013	-	-
Finland, national	1953-2014	1953-2014	1973-2014	1965-2014
Finland, regional	1953-2014	1953-2014	1973-2014	-
Greenland	1968-2014	1983-2014	-	-
Iceland, national	1955-2014	1951-2014	1975-2014	1965-2014
Iceland, regional	1971-2014	1971-2014	1991-2014	-
Norway, national	1953-2014	1953-2014	1973-2014	1965-2014
Norway, regional	1953-2014	1953-2014	1973-2014	-
Sweden, national	1960-2014	1952-2014	1980-2014	1965-2014
Sweden, regional	1970-2014	1970-2014	1990-2014	-

Years covered

Incidence and mortality have been updated to include 2014 data for all counties except for Faroe Islands where mortality now is available to the end of 2013.

Animated maps

Animated maps based on municipality divisions for incidence 1971-2010 and mortality 1971-2003 are included.

Prediction

Updated population predictions from the national statistical bureaus have been included in the update for the prediction of cancer incidence and mortality. For Denmark, Iceland, Finland and Norway, regional predictions are also included while this is still missing for Sweden.

Survival

Survival has been updated for the 5 bigger countries to show the latest cohort of diagnosis 2010-2014 with follow-up through 2015 for death and emigration except for Finland with follow-up through 2014. This means that we now have survival for 50 years in ten 5-year cohorts.

Errors

In version 7.0 to 7.2 (December 2014 to July 2016) the survival estimates for Sweden for the years 1974-1993 were underestimated, in particular for prostate, brain, kidney, leukaemia and small intestines cancers. This was due to inclusion of cases only known from autopsies in Sweden in the survival calculations. Such cases are usually excluded. Estimates of 1- and 5-year relative survival for the group "All sites but non-melanoma skin cancer" were up to 5% point too low for cases diagnosed in 1974-1993. Since that time period, the proportion of cancers found by autopsy alone has decreased in Sweden and from 1999, the underestimation has been 1-2% point. The error has now been rectified, leading to an overall improvement in Swedish cancer survival.

In the present version 7.3, Swedish cancer deaths from gallbladder 1971-1996 seem to have been put into the liver entity. This will be corrected in the next update

Permission to handle data in Denmark

We have acquired permission from the Danish Data Protection Agency to receive and use incidence, mortality and status data from the other Nordic countries for NORDCAN update and for further development including information on stage, treatment, comorbidity and education. This was a condition from Sweden for delivery of data for the 7.3 version.

Memorandum of Understanding

A memorandum of understanding on NORDCAN data, software and secretariat has been made between ANCR and Danish Cancer Society for the period 2016-2018. The director of DCS has asked the Department of Documentation & Quality to host the secretariat.

Use of NORDCAN

The cancer societies in Denmark and Finland directly use NORDCAN statistics on their information web-sites and the Faroe Islands use NORDCAN information in their yearly report. Norway had NORDCAN as a special theme in their annual report for 2012 published in 2013.

NORDCAN is used as a "playing ground" for development of international cancer statistics at IARC and is available from their web-pages <http://gco.iarc.fr/> under databases. It is used all over the world but of course most intensively in the Nordic countries. USA, the UK, Germany and France were big users, but visits were also made from South America. Australia, Japan, China, India and Africa.

In the user statistic for 2016, NORDCAN had a daily average of 95 visits by 57 different users.

Next update

In NORDCAN version 7.3 in July 2016, survival estimates 1965-2014 were included, so we did not need a further update in 2016.

At the NORDCAN meeting in October 2016 we decided to aim for next update in June 2017 with incidence and mortality 2015, survival 1966-2015. In the meantime Finland has

informed us that they would not be able to deliver data before June. The NORDCAN group has then decided to postpone the update to September.

We hope to include:

- New data dictionary including cancers that in the newest ICD-O-3 update has changed to be considered malignant.
- Animated maps for incidence and mortality will be updated.
- Rewriting of the front page with more praise of the database
- Tables with verification of cancers
- Tables with exclusions from survival analyses
- A menu point with a FAQ
- Link to Eero's tables on data collection methods and quality of the cancer registration in the Nordic countries to replace the survey from 2000
- Link to tables on screening activity made by the NordScreen group

Ideas for further development of NORDCAN

When complete follow-up for death and emigration is assured in Faroe Islands and Greenland, prevalence and survival can be considered.

Tables on the available TNM-stage distribution and stage-specific survival.

Comparison of cancer treatment, comorbidity and education for selected sites between the Nordic countries and the influence on survival.

Funding of future development/perspectives

NCU gave in December 2015 a grant to a research project "NORDCAN development; Differences in cancer survival in the Nordic countries: the role of stage at presentation, treatment, co-morbidity and education" for one year with a possible extension for two more years. The work plan for the first year include collection and analysis of TNM-variables for all available sites, applications for data collection of the other variables and start of documentation and validation for 4-5 cancer.

The amount granted (55000 EUR) was lower than applied for.

Status: As part of the data delivery for the 2014-update, TNM data were delivered from Denmark, Iceland, Norway and Sweden.

In Sweden and Denmark TNM registration is compulsory from 2003 and 2004, respectively, in Denmark with no indication of whether registration is clinical or pathologic/postsurgical and in Sweden with a variable telling the type. In Norway, some TNM registrations are found in the cancer register and for some sites also pTNM from clinical databases. In Iceland c and pTNM exist for some sites. In the coming spring the distributions will be further studied.

Funding of operation of the secretariat

An application by ANCR for continued update and quality control of the existing NORDCAN database and software from strategic funds from NCU resulted in yearly funding of 35 500 Euro for a 3-year period 2016-2018.

In October 2016, the ANCR-board specified budget and duties for the NORDCAN Secretariat staffed with the equivalent of a ¼ FTE employee.

As a response for 2016, this report is supplemented with:

- A financial report from NORDCAN secretariat for 2016
- A List of Scientific literature using NORDCAN, searched in PubMed
- NORDCAN user statistics 2016
- Description of the NORDCAN update process

Financial report for NORDCAN secretariat 2016

The yearly grant from NCU for the years 2016, 2017 and 2018 is 35 500 Euro

Two NORDCAN meetings have been held in 2016 at Danish Cancer Society and 1 update was made in July 2016 including 2014-data for incidens, mortality, prevalence and survival

NORDCAN meeting 6-7 April 2016	DKr
Meals and meeting costs	4 972.00
Accommodation 5 persons	4 845.90
Airfares and transportation	<u>13 707.20</u>
	23 525.10
 NORDCAN meeting 25-26 October 2016	
Meals and meeting costs	3 947.20
Accommodation 5 persons	4 500.00
Airfares and transportation	<u>10 176.03</u>
	18 623.23
 Secretariat 2016	
Salaries, senior statistician (2 month) and data manager (1 month)	193 000.00
Office (IT etc)	<u>10 000.00</u>
	203 000.00
 Total for 2016	DKr 245 148.33
	In Euro 32 686.44
 Yearly survival calculation financed by Danish Cancer Society	DKr 165 000.00
3 months extra salary	In Euro 22 000.00

Scientific literature using NORDCAN, searched in PubMed

Studies using NORDCAN as a primary data source:

1. Højberg L, Gad D, Gyldenkerne N, Bastholt L; Academy of Geriatric Cancer Research (AgeCare).. Trends in melanoma in the elderly in Denmark, 1980-2012. *Acta Oncol.* 2016;55 Suppl 1:52-8. doi: 10.3109/0284186X.2015.1114677. PubMed PMID: 26785326.
2. Jensen TK, Jensen NV, Jørgensen SM, Clark P, Lund L; Academy of Geriatric Cancer Research (AgeCare).. Trends in cancer of the urinary bladder and urinary tract in elderly in Denmark, 2008-2012. *Acta Oncol.* 2016;55 Suppl 1:85-90. doi: 10.3109/0284186X.2015.1115122. PubMed PMID: 26784363
3. Azawi NH, Jørgensen SM, Jensen NV, Clark PE, Lund L; Academy of Geriatric Cancer Research (AgeCare).. Trends in kidney cancer among the elderly in Denmark, 1980-2012. *Acta Oncol.* 2016;55 Suppl 1:79-84. doi: 10.3109/0284186X.2015.1115121. PubMed PMID: 26784139.
4. Ør Knudsen A, Schledermann D, Nyvang GB, Mogensen O, Herrstedt J; Academy of Geriatric Cancer Research (AgeCare).. Trends in gynecologic cancer among elderly women in Denmark, 1980-2012. *Acta Oncol.* 2016;55 Suppl 1:65-73. doi:10.3109/0284186X.2015.1115119. PubMed PMID: 26784001.
5. Ocias LF, Larsen TS, Vestergaard H, Friis LS, Abildgaard N, Frederiksen H; Academy of Geriatric Cancer Research (AgeCare).. Trends in hematological cancer in the elderly in Denmark, 1980-2012. *Acta Oncol.* 2016;55 Suppl 1:98-107. doi: 10.3109/0284186X.2015.1115124. PubMed PMID: 26783877.
6. Poulsen MH, Dysager L, Gerke O, Lund L; Academy of Geriatric Cancer Research (AgeCare).. Trends in prostate cancer in elderly in Denmark, 1980-2012. *Acta Oncol.* 2016;55 Suppl 1:74-8. doi: 10.3109/0284186X.2015.1115120. PubMed PMID: 26783651.
7. Ewertz M, Christensen K, Engholm G, Kejs AM, Lund L, Matzen LE, Pfeiffer P, Storm HH, Herrstedt J; Academy of Geriatric Cancer Research (AgeCare).. Trends in cancer in the elderly population in Denmark, 1980-2012. *Acta Oncol.* 2016;55 Suppl 1:1-6. doi: 10.3109/0284186X.2015.1114678. PubMed PMID: 26781233.
8. Dahlrot RH, Poulsen FR, Nguyen NN, Kristensen BW, Hansen S, Holm NV; Academy of Geriatric Cancer Research (AgeCare).. Trends in tumors in the central nervous system in elderly in Denmark, 2008-2012. *Acta Oncol.* 2016;55 Suppl 1:91-7. doi: 10.3109/0284186X.2015.1115123. PubMed PMID: 26781160.
9. Jensen JD, Cold S, Nielsen MH, Jylling AM, Sørensen KL, Larsen LB, Ewertz M; Academy of Geriatric Cancer Research (AgeCare).. Trends in breast cancer in the elderly in Denmark, 1980-2012. *Acta Oncol.* 2016;55 Suppl 1:59-64. doi: 10.3109/0284186X.2015.1115118. PubMed PMID: 26781003.
10. Kristiansen C, Schytte T, Hansen KH, Holtved E, Hansen O; Academy of Geriatric Cancer Research (AgeCare).. Trends in lung cancer in elderly in Denmark, 1980-2012. *Acta Oncol.* 2016;55 Suppl 1:46-51. doi: 10.3109/0284186X.2015.1114676. PubMed PMID: 26769559.
11. Bjerregaard JK, Mortensen MB, Pfeiffer P; Academy of Geriatric Cancer Research (AgeCare).. Trends in cancer of the liver, gall bladder, bile duct, and pancreas in elderly in Denmark, 1980-2012. *Acta Oncol.* 2016;55 Suppl 1:40-5. doi: 10.3109/0284186X.2015.1114675. PubMed PMID: 26767397.
12. Brændegaard Winther S, Baatrup G, Pfeiffer P, Qvortrup C; Academy of Geriatric Cancer Research (AgeCare).. Trends in colorectal cancer in the elderly in Denmark, 1980-2012. *Acta Oncol.* 2016;55 Suppl 1:29-39. doi:10.3109/0284186X.2015.1114674. PubMed PMID: 26765865.
13. Schønnemann KR, Mortensen MB, Krogh M, Holtved E, Andersen MM, Pfeiffer P; Academy of Geriatric Cancer Research (AgeCare).. Trends in upper gastro-intestinal cancer among the elderly in Denmark, 1980-2012. *Acta Oncol.* 2016;55 Suppl 1:23-8. doi: 10.3109/0284186X.2015.1114673. PubMed PMID: 26765771.
14. Johansen J, Grau Eriksen J; Academy of Geriatric Cancer Research (AgeCare).. Trends in cancer of the head and neck in the elderly in Denmark, 1980-2012. *Acta Oncol.* 2016;55 Suppl 1:13-8. doi: 10.3109/0284186X.2015.1114672. PubMed PMID: 26760291.
15. Storm HH, Engholm G, Hakulinen T, Tryggvadóttir L, Klint A, Gislum M, Kejs AM, Bray F. Survival of patients diagnosed with cancer in the Nordic countries up to 1999-2003 followed to the end of 2006. A critical overview of the results. *Acta Oncol.* 2010 Jun;49(5):532-44.
16. Engholm G, Gislum M, Bray F, Hakulinen T. Trends in the survival of patients diagnosed with cancer in the Nordic countries 1964-2003 followed up to the end of 2006. Material and methods. *Acta Oncol.* 2010 Jun;49(5):545-60.
17. Hakulinen T, Tryggvadóttir L, Gislum M, Storm HH, Bray F, Klint A, Engholm G. Trends in the survival of patients diagnosed with cancers of the lip, oral cavity, and pharynx in the Nordic countries 1964-2003 followed up to the end of 2006. *Acta Oncol.* 2010 Jun;49(5):561-77.
18. Klint A, Engholm G, Storm HH, Tryggvadóttir L, Gislum M, Hakulinen T, Bray F. Trends in survival of patients diagnosed with cancer of the digestive organs in the Nordic countries 1964-2003 followed up to the end of 2006. *Acta Oncol.* 2010 Jun;49(5):578-607.

19. Hakulinen T, Engholm G, Gislum M, Storm HH, Klint A, Tryggvadóttir L, Bray F. Trends in the survival of patients diagnosed with cancers in the respiratory system in the Nordic countries 1964-2003 followed up to the end of 2006. *Acta Oncol.* 2010 Jun;49(5):608-23.
20. Tryggvadóttir L, Gislum M, Bray F, Klint A, Hakulinen T, Storm HH, Engholm G. Trends in the survival of patients diagnosed with breast cancer in the Nordic countries 1964-2003 followed up to the end of 2006. *Acta Oncol.* 2010 Jun;49(5):624-31.
21. Klint A, Tryggvadóttir L, Bray F, Gislum M, Hakulinen T, Storm HH, Engholm G. Trends in the survival of patients diagnosed with cancer in female genital organs in the Nordic countries 1964-2003 followed up to the end of 2006. *Acta Oncol.* 2010 Jun;49(5):632-43.
22. Bray F, Klint A, Gislum M, Hakulinen T, Engholm G, Tryggvadóttir L, Storm HH. Trends in survival of patients diagnosed with male genital cancers in the Nordic countries 1964-2003 followed up until the end of 2006. *Acta Oncol.* 2010 Jun;49(5):644-54.
23. Engholm G, Hakulinen T, Gislum M, Tryggvadóttir L, Klint A, Bray F, Storm HH. Trends in the survival of patients diagnosed with kidney or urinary bladder cancer in the Nordic countries 1964-2003 followed up to the end of 2006. *Acta Oncol.* 2010 Jun;49(5):655-64.
24. Tryggvadóttir L, Gislum M, Hakulinen T, Klint A, Engholm G, Storm HH, Bray F. Trends in the survival of patients diagnosed with malignant melanoma of the skin in the Nordic countries 1964-2003 followed up to the end of 2006. *Acta Oncol.* 2010 Jun;49(5):665-72.
25. Bray F, Engholm G, Hakulinen T, Gislum M, Tryggvadóttir L, Storm HH, Klint A. Trends in survival of patients diagnosed with cancers of the brain and nervous system, thyroid, eye, bone, and soft tissues in the Nordic countries 1964-2003 followed up until the end of 2006. *Acta Oncol.* 2010 Jun;49(5):673-93.
26. Storm HH, Klint A, Tryggvadóttir L, Gislum M, Engholm G, Bray F, Hakulinen T. Trends in the survival of patients diagnosed with malignant neoplasms of lymphoid, haematopoietic, and related tissue in the Nordic countries 1964-2003 followed up to the end of 2006. *Acta Oncol.* 2010 Jun;49(5):694-712.
27. Storm HH, Kejs AM, Engholm G, Tryggvadóttir L, Klint A, Bray F, Hakulinen T. Trends in the overall survival of cancer patients diagnosed 1964-2003 in the Nordic countries followed up to the end of 2006: the importance of case-mix. *Acta Oncol.* 2010 Jun;49(5):713-24.
28. Engholm G, Ferlay J, Christensen N, Bray F, Gjerstorff ML, Klint A, Køtlum JE, Olafsdóttir E, Pukkala E, Storm HH. NORDCAN--a Nordic tool for cancer information, planning, quality control and research. *Acta Oncol.* 2010 Jun;49(5):725-36.

Other studies using NORDCAN:

1. Gottschau M, Mellemkjaer L, Hannibal CG, Kjaer SK. Ovarian and tubal cancer in Denmark: an update on incidence and survival. *Acta Obstet Gynecol Scand.* 2016 Oct;95(10):1181-9. doi: 10.1111/aogs.12948. PubMed PMID: 27454324.
2. Carlberg M, Hedendahl L, Ahonen M, Koppel T, Hardell L. Increasing incidence of thyroid cancer in the Nordic countries with main focus on Swedish data. *BMC Cancer.* 2016 Jul 7;16:426. doi: 10.1186/s12885-016-2429-4. PubMed PMID: 27388603; PubMed Central PMCID: PMC4937579.
3. Zadnik V, Žagar T, Žakelj MP. Cancer Patients' Survival: Standard Calculation Methods And Some Considerations Regarding Their Interpretation: POPULACIJSKO PREŽIVETJE BOLNIKOVA RAKOM: UPORABA RAZLIČNIH PRISTOPOV IN PROBLEMI INTERPRETACIJE REZULTATOV. *Zdr Varst.* 2016 Feb 11;55(2):134-41. doi: 10.1515/sjph-2016-0012. Review. PubMed PMID: 27284384; PubMed Central PMCID: PMC4845767.
4. Altobelli E, D'Aloisio F, Angeletti PM. Colorectal cancer screening in countries of European Council outside of the EU-28. *World J Gastroenterol.* 2016 May 28;22(20):4946-57. doi:10.3748/wjg.v22.i20.4946. PubMed PMID: 27239121; PubMed Central PMCID: PMC4873887.
5. Rizzi S, Thinggaard M, Engholm G, Christensen N, Johannesen TB, Vaupel JW, Lindahl-Jacobsen R. Comparison of non-parametric methods for ungrouping coarsely aggregated data. *BMC Med Res Methodol.* 2016 May 23;16:59. doi: 10.1186/s12874-016-0157-8. PubMed PMID: 27216531; PubMed Central PMCID: PMC4877978.
6. Antoni S, Soerjomataram I, Møller B, Bray F, Ferlay J. An assessment of GLOBOCAN methods for deriving national estimates of cancer incidence. *Bull World Health Organ.* 2016 Mar 1;94(3):174-84. doi: 10.2471/BLT.15.164384. PubMed PMID: 26966328; PubMed Central PMCID: PMC4773935.
7. Crocetti E, Dyba T, Martos C, Randi G, Rooney R, Bettio M. The need for a rapid and comprehensive adoption of the revised European standard population in cancer incidence comparisons. *Eur J Cancer Prev.* 2016 Feb 25. [Epub ahead of print] PubMed PMID: 26919133.
8. Grimsrud TK, Skaug HK, Larsen IK. Lung cancer – changes in incidence by gender, age and county of residence 1984-2013. *Tidsskr Nor Laegeforen.* 2015 Nov 3;135(20):1844-9. doi: 10.4045/tidsskr.14.1424. English, Norwegian. Erratum in: *Tidsskr Nor Laegeforen.* 2015 Nov 17;135(21):1924. *Tidsskr Nor Laegeforen.* 2015 Dec 15;135(23-24):2131. PubMed PMID: 26534811.
9. Kalseth J, Halvorsen T, Kalseth B, Sarheim Anthun K, Peltola M, Kautiainen K, Häkkinen U, Medin E, Lundgren J, Rehnberg C, Másdóttir BB, Heimisdóttir M, Bjarnadóttir HH, Køtlum JE, Kilsmark J, Halsteinli V. Cross-country comparisons of health-care costs: the case of cancer treatment in the

31. Marså K, Johnsen NF, Bidstrup PE, Johannesen-Henry CT, Friis S. Social inequality and incidence of and survival from male genital cancer in a population-based study in Denmark, 1994-2003. *Eur J Cancer*. 2008;44:2018-29.
32. Jensen KE, Hannibal CG, Nielsen A, Jensen A, Nøhr B, Munk C, Kjaer SK. Social inequality and incidence of and survival from cancer of the female genital organs in a population-based study in Denmark, 1994-2003. *Eur J Cancer*. 2008;44:2003-17.
33. Hannibal CG, Cortes R, Engholm G, Kjaer SK. Survival of ovarian cancer patients in Denmark: excess mortality risk analysis of five-year relative survival in the period 1978-2002. *Acta Obstet Gynecol Scand*. 2008;87(12):1353-60. doi: 10.1080/00016340802483000. PubMed PMID: 18951210.
34. Carlsen K, Høybye MT, Dalton SO, Tjønneland A. Social inequality and incidence of and survival from breast cancer in a population-based study in Denmark, 1994-2003. *Eur J Cancer*. 2008;44:1996-2002.
35. Dalton SO, Steding-Jessen M, Engholm G, Schüz J, Olsen JH. Social inequality and incidence of and survival from lung cancer in a population-based study in Denmark, 1994-2003. *Eur J Cancer*. 2008;44:1989-95.
36. Egeberg R, Halkjaer J, Rottmann N, Hansen L, Holten I. Social inequality and incidence of and survival from cancers of the colon and rectum in a population-based study in Denmark, 1994-2003. *Eur J Cancer*. 2008;44:1978-88.
37. Baastrup R, Sørensen M, Hansen J, Hansen RD, Würtzen H, Winther JF. Social inequality and incidence of and survival from cancers of the oesophagus, stomach and pancreas in a population-based study in Denmark, 1994-2003. *Eur J Cancer*. 2008;44:1962-77.
38. Andersen ZJ, Lassen CF, Clemmensen IH. Social inequality and incidence of and survival from cancers of the mouth, pharynx and larynx in a population-based study in Denmark, 1994-2003. *Eur J Cancer*. 2008;44:1950-61.
39. Dalton SO, Steding-Jessen M, Gislum M, Frederiksen K, Engholm G, Schüz J. Social inequality and incidence of and survival from cancer in a population-based study in Denmark, 1994-2003: Background, aims, material and methods. *Eur J Cancer*. 2008;44:1938-49.
40. Menvielle G, Kunst A. Social inequalities in cancer incidence and cancer survival: Lessons from Danish studies. *Eur J Cancer*. 2008;44:1933-7.
41. Nagenthiraja K, Ewertz M, Engholm G, Storm HH. Incidence and mortality of pancreatic cancer in the Nordic countries 1971-2000. *Acta Oncol*. 2007;46(8):1064-9. PubMed PMID: 17952708.
42. Bray F, Wibe A, Dørum LM, Møller B. [Epidemiology of colorectal cancer in Norway]. *Tidsskr Nor Laegeforen*. 2007 Oct 18;127(20):2682-7. Norwegian. PubMed PMID: 17952152.
43. Levi F, Ferlay J, Galeone C, Lucchini F, Negri E, Boyle P, La Vecchia C. The changing pattern of kidney cancer incidence and mortality in Europe. *BJU Int*. 2008;101:949-58. Ferlay J, Autier P, Boniol M, Heanue M, Colombet M, Boyle P. Cancer Incidence and Mortality in Europe, 2006. *Annals of Oncology* 2007; 16:481-488.

Description of the NORDCAN update process

Data in NORDCAN stem from the national Cancer Registers, Cause of Death Registers and Population Registers in the Nordic countries (Denmark, Faroe Islands, Finland, Greenland, Iceland, Norway and Sweden). Each of the registers make yearly updates. Earlier, NORDCAN was updated twice per year, a spring version with update for incidence, mortality and prevalence for the countries who were able to deliver new data and a fall version including the yearly update for all the countries and with calculated cancer survival. Presently, all countries are able to deliver data in spring. Only one version was needed in 2016 (including 2014-data) and we expect the similar in 2017 (with 2015-data) with expected update in early June.

Call for data

At the second NORDCAN meeting each year, plans are made for update the coming year with a time schedule for delivery of the national data and a plan for new facilities. Registries are reminded of delivery by mail from the Secretariat when delivery is due.

Datasets for the update process from each country

Incidence: study no, tumor no, date of birth, sex, date of diagnosis, ICD-O-3 code (topography, morphology, behaviour), method of verification (including DCO and incidental autopsy, microscopically verified), country, region and municipality of address at date of diagnosis, stage (T, N and M) at diagnosis, date of end of follow-up, status at end of follow-up (death, emigration, end of follow-up). (Data are delivered for all years of diagnosis. Date and status of end of follow-up stem from population register).

Mortality: date of birth, sex, date of death, underlying cause of death (ICD-10), country, region and municipality of address at date of death. (Data are in principle only delivered for the latest year since mortality registrations are not expected to change over time, but Finland delivers with a special variable indicating if the patient died from the cancer as part of the incidence file, Norway delivers as a table)

Population numbers (midyear) for each calendar year by 5-year age-groups, sex and address (country, region and municipality)

Population mortality by sex, age (1-year groups) and calendar year for each country.

Checking and conversion process

Incidence data (ICD-O-3) are checked using the IARCrgTools-program with outputfiles of errors and warnings. These lists are sent back to the registries for verification. Multiple cancers are identified according to international rules (IARC/IACR) using another part of the IARCrgTools-program. Inclusion and exclusion criterias for each country are checked. The checked ICD-O-3 codes are converted to ICD-10 and grouped according to NORDCAN entities.

The received incidence data are supplemented with the NORDCAN entity code and a variable indicating if and why a tumour is not included (multiple cancer, errors, not converted to a NORDCAN entity) and sent back to the registry delivering data. This file can be used for delivering individual data from each Registry to

Nordic projects with comparable data converted according to common international rules and comparable to the rates in the NORDCAN database.

Cancer mortality codes are grouped into NORDCAN entities. Conversions from ICD-7, ICD-8 and ICD-9 might be necessary.

Prevalence data (patients alive) by the end of each year are calculated for patients diagnosed 1, 3, 5, 10 and all earlier years. Prevalence data are shown from 20 years after the first year of incidence data. For patients with more than one diagnosis, the earliest diagnosis is used for each entity group. Prevalence data are not shown for Faroe Islands and Greenland since complete follow-up for death and emigration is not assured

Data delivery from the secretariat

Sent to IARC

Tabulated data by sex, year, age (5-year age groups up to 85+) and country and region are sent to J. Ferlay at IARC

- Incidence data by year and age of diagnosis and entity
- Mortality data by year and age of death and entity
- Prevalence data by age and years since diagnosis at the end of each year and entity
- Population data (midyear and end year)
- Population forecasts

Tables of percentage microscopically verified cases will be sent for the next update for inclusion in NORDCAN.

Sent to Finnish Cancer Registry for animated maps

Animated maps of incidence and mortality are made at the Finnish Cancer Registry. For this, incidence, cancer mortality and population data by entity, sex, age, year and municipality are sent.

Calculation of cancer Survival

Relative survival is defined as the observed survival for patients divided by the expected survival for the population with the same age-profile as the patient group. Cancer survival is calculated for ten 5-year periods for the latest 50 years. Thus, the period covered will change with each update. It is made for Denmark, Finland, Iceland, Norway and Sweden, only countries and not regions. Survival is not calculated for Faroe Islands and Greenland since complete follow-up for death has not yet been assured.

Data and methods for 1-, 5- and 10-year relative survival

The converted incidence datasets are used. All cancer diagnoses are included in the calculations, i.e. patients with two cancer diagnoses are included twice with a record for each date of diagnosis and entity. Cancer diagnoses found as Death certificate only (DCO) or only from autopsy are excluded as well as patients 90 years or older at diagnosis. Follow-up for death can in most countries be searched for at least one more year than cancer diagnosis, i.e. in NORDCAN version 7.3 patients diagnosed in 2014 have been followed up for death through 2015.

Calculation of expected survival use population mortality. Population mortality from the different countries are fetched from the databanks of the national statistical bureaus.

Calculations use Paul Dickman's macros in STATA with actuarial methods for observed survival and Ederer II methods for expected survival. NORDCAN generally use cohort methods, following up patients for death for 1 and 5 years after diagnosis and also 10 years for breast and prostate cancers. For the later 5-year periods,

not all patients can be followed up for 5 or 10 years, and calculations supplement with survival experience for patients diagnosed earlier years, called hybrid methods.

Survival is only calculated for cells (by country, entity, age-group and 5-year calendar period of diagnosis) including at least 10 cases. Cells with too small numbers are sought to be combined with neighbouring cell(s) to make a common calculation possible.

Age-standardisation uses the International Cancer Survival Standards (ICSS).

Survival data sent to IARC

The calculated 1- and 5-year (and 10) relative survival including 95% confidence intervals for each entity, sex and country by survival age-groups and age-standardised survival are sent to J. Ferlay at IARC for inclusion in NORDCAN.

Also Figures showing improvement in survival over the last 15 years for Denmark, Finland, Norway and Sweden are sent.

Specific tables showing the excluded number of patients by entity, sex and period of diagnosis are intended to be included from the update with 2015-data in Spring 2017.

Funding of survival

In the application for funding, survival calculations were only planned to take place every 3 or 5 years. Danish Cancer Society supplement the funding to make yearly survival updates possible.

Updating texts and language versions

The secretariat sends suggestions to updated texts in English to the NORDCAN group by mail. When revised texts are accepted after a mail-discussion, each country representative is asked to translate the new and revised texts to his/her national language.

Test version and acceptance by each country

When data for the update is received from the secretariat, J. Ferlay at IARC makes a test version in English (not yet including cancer fact sheets).

The Secretariat and country representatives are asked to check data. This can include comparison of time trends for the all cancer group in the old and new version, comparison of tables by entity of incidence, mortality and prevalence for the latest year in the old version compared to the same year in the new version, comparison of age-specific curves between the old and new version. The aim is to look for jumps in data, missing data, wrong data and big discrepancies to the previous version. Survival trend should also be checked in a similar way.

Each representative has to accept the update (by mail). Then the final version can be publicly updated (including cancer fact sheets) in each of the six language versions.

Each country representative is responsible for checking their national version for text and data.



Ragnheiður Haraldsdóttir,
Chairman of the board
Nordic Cancer Union

**Oslo University Hospital
Clinical Cancer Research Unit**
Section for Clinical Cancer Research
Department of Oncology
The Norwegian Radium Hospital
P.O. Box 4950, Nydalen
N-0424 Oslo, Norway

Phone: +47 22 93 40 00
www.nordicnect.org

February 10th, 2017

Report

Financial support for funding of a 50 % project-coordinator position at Secretariat for Nordic Network for Early Cancer Trials (Nordic NECT)

The primary function of the Secretariat is to act as the key operational interface with internal and external services to develop, implement, maintain and improve operational processes within Nordic NECT and to contribute to further Nordic collaboration. The Secretariat will be the network's primary point of contact and contribute to establishing a well-functioning Secretariat within Nordic NECT.

To further develop the network and streamline the organization and function, the Nordic NECT established a Secretariat in August 2016, situated in Norway at Oslo Cancer Cluster Incubator (located next to Oslo University Hospital, Radiumhospitalet). The Secretariat is the *contact point* for pharmaceutical companies, Clinical Research Offices (CRO), investigators and other who want to perform early clinical cancer trials in the Nordic region. The Secretariat will liaison information on new early cancer trials to the individual sites, collect their feedback of interest, establish trial project groups, translate patient informed consent in each Nordic language, create a database for trials and update and develop the networks WEB-site.

In April 2016 Nordic NECT made an advertisement in all the Nordic countries for a Project Manager/Secretary 50-100% position for 3 years. There were 4 relevant applicants, and Kirsten Thorin Hagene was chosen.

Kirsten Thorin Hagene started working 50 % for the Nordic NECT Secretariat in August 2016. Kirsten has 11 years of experience in lab. research (micrometastases and drug discovery), at respectively the Institute for Cancer Research at Oslo University Hospital and Neurosearch/Abbott laboratories. Since 2009 she has been involved in early cancer trials as Site Project Manager at the Clinical Cancer Research Unit at Oslo University Hospital. Kirsten shares a 50% position in the Nordic NECT Secretariat and 50% at the Clinical Cancer Research Unit.

Activities 2016-2017:

- Setting up the office
- Updating the Nordic NECT web page: There have been an increasing number of clinical studies published on the WEB-site, as of 09.02.2017 a total of 1100 studies are open for inclusion.
<http://www.nordicnect.org/>
- Facilitating meetings
- Establishing a good network with the sites and members of Nordic NECT
- October 11th, 2016: Nordic NECT meeting (members), Rigshospitalet, Copenhagen, Denmark

Activities to come:

- Site Visits: To improve the collaboration within the Nordic NECT, Kirsten plans to visit each Nordic NECT site, preferable within June 2017.
- March 14th, 2017: : Nordic NECT meeting (members), Helsinki University Hospital, Helsinki, Finland
- May 19th, 2017: NRI Conference 2017, Oslo, Norway

At the next NRI-Conference Nordic NECT will facilitate a workshop for *Nordic Cross border patients for Clinical Trials*. Draft information has been published at the [NRI webpage](#). This will be updated as soon as the program is finalized. Nordic NECT Secretariat is very much involved in the planning of this upcoming Nordic meeting, partly funded by Nordic Trial Alliance through NordForsk.

The aim of the workshop is to create awareness of the collaboration potentials, identify hurdles preventing patients from participating in clinical trials cross border, establish working groups addressing regulatory requirements, patient information challenges, language differences etc.

The workshop will address the cross border challenges with lectures from regulatory authorities, payers, oncologists, patient representatives and healthcare politicians.

Economy:

The Secretariat is funded for a 50 % position by grants from NCU, started in August 2016. Enclosed the financial report for 2016 (in Norwegian).

We would use this opportunity to thank the Nordic Cancer Union for your support and grant. Your support has made it possible to establish a Secretariat for Nordic NECT!

If you have any questions related to the report or other business, please let us know and we will be happy to accommodate.

Steinar Aamdal
Professor emeritus, MD, PhD
Dept. of Oncology
Oslo University Hospital
Chairman of Nordic NECT

Utviklingsrapport for enkeltprosjekt januar - desember 2016

Prosjekt: 35187 DNR 155013 v/PFB - 3 års lønnsmidler 50 % til en prosjektkoordinatorstilling

Totale kostnader/inntekter vises for alle prosjekter

		Periode					Totalt
		2016-08	2016-09	2016-10	2016-11	2016-12	
5 Personalkostnader	5004 Arbeidstakers andel pensjon 2%	-433	-483	-458	-458	-516	-2349
	5048 Andre faste tillegg		2500	1250	1250	1250	6250
	5090 Påløpte feriepenger fast lønn "ren" fra lønssystem	2600	2900	2750	2750	3097	14097
	5140 Engasjement	21667	21667	21667	21667	24555	111221
	5400 Arbeidsgiveravgift	3055	3408	3231	3231	3638	16563
	5401 Arbeidsgiveravgift avsatte feriepenger	367	409	388	388	437	1988
	5409 Periodisering arbeidsgiveravgift	-61	-68	-65	-65	-73	-331
	5410 Pensjonskostnad eks AFP	4052	4519	4285	4285	4825	21967
	5414 Arbeidstakers andel pensjon 2%	433	483	458	458	516	2349
	5416 Arbeidsgiveravgift av pensjonskostnad, tjenestepensj.	571	637	604	604	680	3097
6 Andre driftskostnader	5418 Periodiseringskonto arbeidsgiveravgift pensjonskostnader	61	68	65	65	73	331
	Sum	32311	36039	34175	34175	38482	175183
	6901 Mobiltelefoni			357	417	554	1328
7 Andre driftskostnader	Sum			357	417	554	1328
	7150 Diett og nattillegg, oppgavepl.				480		480
	Sum				480		480
Totalt		32311	36039	34532	35072	39036	176991

[Firmanavn]

Til: NCU Board – Meeting in Stockholm 16.02.17
Fra: The Norwegian Cancer Society
Kopi:
Dato: 3. februar 2017
Re: NCU-research: change in guidelines - Eligibility of the Principal investigator

Background

There are two documents that regulates NCU research. One is the "NCU research strategy", the other "NCU Research Grant Guidelines". The "NCU Research Grant Guidelines" states that:

"The Nordic Cancer Union (NCU) provides funding to support and stimulate collaborative cancer research within the Nordic countries. Researchers working in two Nordic countries or more must be involved in the project. The research project must be cancer relevant and the effect of collaboration should be synergistic."

At the meeting in the Scientific Committee last year, there was some confusion among the participants regarding the interpretation of the Guidelines as to the affiliation of Principal Investigators.

As a point in case, the Principal Investigator in one of last year's applications was German and worked at a German research institute, but at the same time had co-applicants from four of the Nordic countries. The Scientific Committee discussed the application and it was unclear whether the application would qualify for funding since neither the NCU Application Guidelines nor Strategy unambiguously states that the PI must belong to a Nordic institution.

The conclusion from the discussion in the Scientific Committee was not to fund the project. Although the PI afterwards clarified that he had in fact a double affiliation to both a German research institute and to a Nordic University, the project did not end up among the funded projects.

To avoid any misunderstanding in the future we recommend that we add the following paragraph to the requirements: "The principal investigator of a research project must be affiliated with a Nordic research institution"

memo

Decision by the NCU Board

The requirements regarding the principal investigator is added to the NCU-research guidelines. The requirements will then be:

The Nordic Cancer Union (NCU) provides funding to support and stimulate collaborative cancer research within the Nordic countries. Researchers working in two Nordic countries or more must be involved in the project. The principal investigator of a research project must be affiliated with a Nordic research institution. The research project must be cancer relevant and the effect of collaboration should be synergistic."

To the Board of the NCU

From Ragnheiður Haraldsdóttir, chairman

February 6th 2016

Applications for NCU strategic funds

1.0 Some points from the NCU strategy on strategic funds:

- The Nordic Cancer Union provides funding for projects of high standard within the field of cancer in line with its statutes.
- The implementation of the strategic improvement projects aim at ameliorating relevant cancer problems in the member countries. 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 as well as this strategy.
- These improvements projects must be uniquely suited to be implemented in part at least in the Nordic countries, and should as a rule be aimed at enhancing infrastructure and cooperation. Preferably, health care professionals and/or researchers in two or more Nordic countries should be involved in the projects and the effects of collaboration should be synergistic.
- As major emphases of the NCU are to enhance collaborative research, research-related projects are of special interest to the NCU. Comparisons between the Nordic countries are essential for the development and work on diverse cancer research programmes, enhancing the likelihood of higher efficiency and results.
- The NCU thus provides funding to support the implementation of high quality projects of relevance to cancer within the Nordic countries with added Nordic value, based on common Nordic priorities and current interests as identified by the board of the Nordic Cancer Union at any given point in time.
- Applications and proposals will be presented to the NCU board following their reception by the chairman of the board. They will be reviewed and evaluated at the earliest opportunity, but will at times need external or internal evaluation that can be time consuming.

Initiative for strategic funding should mainly come from the NCU board, although funding projects suggested from others can be considered.

2.0 The following applications have been submitted:

1. Nordic meeting of young cancer patients to be held in Iceland in May 2016 (attch.). The application is from from Kraftur, the Icelandic association of young cancer patients. Nordic

organizations working with and for younger cancer patients and survivors, about 20 participants in all. The sum applied for is 40.000 NOK.

2. The NORDSCREEN project (attch.) aims to develop a publicly available web-based interactive tool/application to access, compile and visualize standardised performance and outcome indicators of cancer screening, based on up-to-date Nordic cancer screening register data. The concept is based on the NORDCAN equivalent platform for cancer burden and will build on experiences from that collaborative project.

The five Nordic countries have national screening registers with high completeness on organised screening invitations and results. However, comparison of actual performance and outcome of screening across programmes is currently difficult. Such direct comparison could prove very informative and produce valuable data to support screening policy development and implementation. It is important, also from an ethical perspective, that data on quality is made available to the public, to the media, to service providers, and to policy-makers. These target groups need an easily accessible tool for analyzing and visualizing quality indicators that reflect the impact of policy decision in comparison with neighboring Nordic countries. A joint Nordic effort to standardize reporting of performance and outcome indicators and make these publicly available will have the potential to stimulate collaborative research, quality improvement in screening, and translate into improved health outcomes.

Ragnheiður Haraldsdóttir

- SØKNAD
- ARBEIDSFLYT
- KOMMUNIKASJON
- UTSKRIFTER
- ANNET

#187894 NORDIC CANCER MEETING IN ICELAND

UTLYSNING: KONGRESSTØTTE - TANNLEGE OLAF AASE OG FRUES LEGATSØKER: RAGNHEIDUR DAVIDSDÓTTIR
APPLICATION: #187894 NORDIC CANCER MEETING IN ICELAND

1 / 1

SØKNADSINFO

Søknadsid:
187894

Søker:
Ragnheidur Davidsdottir

Ordning:
Kongresstøtte - Tannlege Olaf Aase og frues legat

Søknadstype:
Tannlege Olaf Aase og frues legat

Opprettet:
13.10.2016

Innsendt:
16.11.2016

OM ARRANGEMENTET

ARRANGEMENTET

Oppgi navnet på arrangør og på seminaret. Deretter ønsker vi en beskrivelse av arrangementet, deltakerne, foredragsholder og kreftrelevansen.

NAVN PÅ ARRANGØR

Kraftur

NAVN PÅ SEMINARET

Nordic cancer

Gi en beskrivelse av arrangementet. (Hva er det faglige innhold og tema for arrangementet, størrelsen på arrangementet, hvordan arrangementet er annonsert / annonseres og annen relevant informasjon)

Beskrivelse av arrangementet

The annual meeting of young people diagnosed with cancer will be held in Iceland in June next year. These people are members of youth organizations. The organizations host the annual meeting every year. This year we (Kraftur) are hosting the Nordic Cancer Survivors conference. It will take place 24. - 28. may 2017.

Gi en beskrivelse av deltakerne (hvilke deltakere er invitert og annen relevant informasjon)

Beskrivelse av deltakere

The idea is that Nordic organizations working with and for young adults affected by cancer will share knowledge and inspire each other in our common efforts. Organizations from Norway, Denmark, Sweden, Finland and Iceland will attend. In all there will be about 20 participants.

BELØP OG BUDSJETT

SØK BELØP

Søkte **totalutgifter** kan ikke overstige NOK 50 000.

Søknadssum (NOK)

40 000

BUDSJETT

Vennligst legg inn et detaljert budsjett/kostnadsoversikt over hvordan de søkte midlene skal benyttes (reise, hotell, kost etc.). Ved dekning av reiseutgifter skal fortrinnsvis økonomi/lavpris billett legges til grunn i budsjettfeltet. Det kan unntaksvis velges et dyrere reisealternativ.

Detaljert budsjett

The participants will pay for the flight themselves but Kraftur pays the expenses concerning food, hotels, tours as well as domestic meeting expenses. SKB (The Icelandic childhood cancer parent Organization) and Kraftur are splitting the expenses. Kraftur has already been promised 200.000 Icelandic kronur from the Ministry of welfare. Estimated cost of domestic transport, accommodation, entertainment and food is about 930.000 ISK. The charge for the meeting facility, which includes a sleeping area for 26 participants, is 300.000 ISK. 6 double rooms in a hotel in Reykjavik one night for 12 people: 160.000 ISK. Food for 4 days for 20 persons and one dinner at a restaurant the last day: 230.000 ISK. (Members of Kraftur and SKB will buy groceries and cook all meals in the meeting facility to minimum the cost) Transportation: Rental fee for mini bus for 4 days: 240.000 ISK. (60.000 pr. day). The meeting facility is located in approx. 100 km. distance east of Reykjavik.

Finnish Cancer Society/Finnish Cancer Registry

NORDSCREEN - Project description

Helsinki, 7 February 2017

Stefan Lönnberg

Project: Interactive joint NORDic database on performance and outcome indicators of cervical cancer SCREENing (NORDSCREEN)

Background

Comprehensive quality assurance is required as an integrated part of population-based cancer screening (Council recommendation of 2 December 2003 on cancer screening [2003/878/EC]), can be considered ethically mandated, and requires the monitoring of quality indicators that are easily communicated to stakeholders for feed-back on programme performance. For maximum impact, these indicators need to be produced in a standardised fashion to allow reliable comparison between programmes, over time, age groups and regions.

Many European countries, and all Nordic countries, report that they have population-based mass screening registries with individually identifiable data on screening participation and outcomes. However, the data is not compiled, analysed and visualized in an easy and standardised manner. Although questionnaires sent to the registries (the EU screening report) provide useful information for policymaking, it is infrequently published and does not fully exploit the potential of the massive amounts of data available. On-line compilation, analysis and visualization of the performance indicators would be needed to support policy-making towards efficient improvements. Publicly available standardised indicators may also motivate programmes to develop and improve routines for data collection and monitoring. The ready availability of indicators, not only for the own country, but for comparator programmes as well, would also greatly ease the provision of relevant and tailored data to decision-makers, the press, and screening providers (in the field of cancer burden, the NORDCAN and GLOBOCAN tools are proof-of-principle of the importance of this).

The five Nordic countries have national screening registers with high completeness on organised screening invitations and results. The screening programmes differ to some extent with respect to policy and direct comparison of actual performance and outcome of screening across programmes is currently difficult. Such direct comparison could prove immensely informative and produce valuable data to support screening policy development and implementation. The Nordic setting is uniquely suited for further research on screening impact and optimisation.

Key performance indicators in cervical, breast, and colorectal cancer screening have been described in the respective European Guidelines for QA in cancer screening. The indicators have since been further developed, together with the data items needed to calculate them, in European collaborations (deliverables of WP5 in EUROUCOURSE; <http://www.eurocourse.org>).

Aim

The aim of NORDSCREEN is to develop and launch a publicly available web-based interactive application to access quality indicators describing the performance and outcomes in Nordic cancer screening programmes. The primary rationale is to inform screening policy development and follow-up of implemented policies. Also, screening managers, screening service providers,

researchers, the media and the screening target population itself should have use of standardized quality information of this kind. The web tool will allow the user to generate graphically displayed evidence-based indicators comparing periods, age-groups, regions, and screening programmes by exercising their choices through an easily understandable interface.

The screening performance visualization tool will allow the identification of areas in need of further quality assurance research and attention. The tool will thus improve the transparency of decision-making, allowing the public to check and explore data relevant for decisions on health policy.

Work plan

The Nordic cervical cancer screening network (restarted in 2014) has already provided some input on the practical aspects of data retrieval and the calculation of indicators. Based on previous work, this project will develop and implement a standardised set of key performance and outcome indicators, and a set of scripts for standardised retrieval (/export) of the required data items from the different collaborating screening registers. The resulting data will be in aggregate form. Finally, a web-based application will be developed for easy, flexible and public access to these data.

Definition of quality indicators

Performance and outcome indicators of screening have been described in the EU guidelines for quality assurance of cancer screening, but are not prioritized and sometimes not entirely unambiguous regarding how they should be calculated. We will prioritize indicators based on strength of association with cancer protection, harms and costs of screening, relevance for policy-making and organisation of screening delivery, and feasibility. The indicators will cover screening intensity, population coverage, screening test performance and the quality of diagnostic assessment and treatment.

Ethico-legal assessment

The legal and ethical frameworks for the assembly of a dynamic database to produce publicly available quality indicators will be mapped in the Nordic setting. A high degree of relevance while protecting personal data safety will be secured within these frameworks, by using technical solutions and options relating to the choice of indicators and the degree of detail and aggregation in the dynamic database. Relevant institutional agreements and ethical permissions will be defined in general and for individual countries.

Development of standard scripts

Standard scripts will be written and implemented in the national screening registers for the extraction and export of the indicator data. It is important that identical calculations are performed for highest possible comparability. The conversion of national database structures to standardised specifications will require a thorough knowledge of the quality, gaps and coding basis of the contributing registers. Therefore collaboration with national experts in each contributing country is essential.

Development of website

The Nordscreen website will be developed with information of the collaborating screening programmes relevant for the interpretation of quality indicators. This information will cover

country-specific screening policy, cancer burden (by linking to / utilising NORDCAN data), details on the quality of available data and general methodology with appraisal of limitations and strengths.

Development of database solution

The solutions for the creation and upkeep of the dynamic source data on quality indicators will be developed as open source tools, be flexible to accommodate the variety of technical solutions in the national registers, be cheap and easy to expand to new countries, allow semi-automated updates of the dynamic indicator database, and conform with the ethicolegal frameworks of personal data protection and high relevance of content.

Development of the on-line graphical analysis tool

The web-site will link to the analysis tool for on-demand graphical display of up-to-date quality indicators comparable across countries or regions, over periods and age-groups. The target audience includes the general public and media, screening managers and service providers, scientists for generation of research hypotheses, and most importantly the policy-makers. By their nature quality indicators will reflect health policy, and the ability to track changes over time and compare with peer programmes in other European countries will be valuable for assessing the effects of policy adjustments. Such a tool would also be helpful in identifying weak links in the screening process within a specific programme highlighted by comparison with others, and in prioritising efforts for quality improvement through change of policy or organisation of screening. Direct comparison of programme quality is currently difficult due to differences in registering practices, calculation of indicators, presentation, publishing, timing and a lack of standardised background information on the organisation of screening.

Current status, schedule and funding gaps

The project has received funding through the NordForsk funded Nordic Information for Action eScience Center (NIASC) hosted by Karolinska Institute, Sweden, for a part-time project coordinator from 1.5.2016 to 31.12.2018. The project has so far defined the first indicators for test coverage in cervical cancer screening, developed the standard script for their calculation from national individual data and produced these indicator data sets for Finland and Norway, and produced an interactive tool for graphically exploring these indicators for testing purposes. Following publication of these indicators on the interactive web-based tool, planned within 2017, the next phase of the project will be to start expanding data coverage to the remaining Nordic countries, to new indicators, and other cancer sites. Representatives of the national registers for cervical cancer screening in Sweden, Iceland and Denmark have been involved in the project planning and are in various phases of planning or preparation to provide test coverage data.

Resources for the development of the interactive web-based tool itself need to be secured, which would either mean a dedicated programmer, or resources for outsourcing of the development work. Expanding the scientist/coordinator part-time position to a full-time position would allow progress to be made more rapidly and also the development of scientific papers comparing the Nordic screening programmes regarding historical development, policy, organisation, results and the currently produced quality indicators, based on the experience and information gathered. Finally participating institutions would require some funding for the local development of IT-solutions for

producing the standardised data, for data retrieval, and the means to organise annual project meetings.

Conclusion

The proposal involves harnessing the potential of the existing rich national registries of cancer screening in the Nordic countries. A first requirement of fully exploiting the potential of data is to make it accessible to potential exploiters. Comparison of indicators with Nordic peers would highlight areas of suboptimal screening performance in individual programmes or regions, and thereby help to direct efforts to improve. The joint data repository with publicly available standardised indicators may also motivate programmes to develop and improve their routines for screening data collection and monitoring. The ready availability of performance indicators, not only concerning the home country, but for comparator programmes as well, would greatly ease the provision of relevant data to decision-makers, the press, and screening providers. The screening data repository could also be useful for identifying areas needing further quality assurance research and attention, thereby acting as a seeding ground for the development of new research projects and quality improvement for better health outcomes in years to come.

Nordic Cancer Union Strategic Funds for Improvement Projects - Application letter

Interactive joint NORDic database on performance and outcome indicators of cancer SCREENing (NORDSCREEN)

Aim

The NORDSCREEN project aims to develop a publicly available web-based interactive tool/application to access standardised, and as far as possible, evidence-based, performance and outcome indicators of cancer screening, based upon up-to-date Nordic cancer screening register data. The concept is based on the NORDCAN equivalent platform for cancer burden and will build on experiences from that collaborative project.

Background

The five Nordic countries have national screening registers with high completeness on organised screening invitations and results. The screening programmes differ to some extent with respect to screening policy, service organisation, and calculation and publication of quality indicators and direct comparison of actual performance and outcome of screening across programmes is currently difficult. Such direct comparison could prove immensely informative and produce valuable data to support screening policy development and implementation. The Nordic setting is uniquely suited for further research on screening impact and optimisation.

Alignment with NCU strategy

In accordance with the general and improvement project strategies of the Nordic Cancer Union (NCU), this project will develop a method and platform to refine and capitalize on the unique existing national screening registries in the Nordic countries. The Nordic setting is unique because of the high quality and completeness of both screening registration (performance) and cancer registration (outcome), that the data go back several decades especially for cancer and cervical screening, and that individual linkage is possible for outcome indicators using unique personal identifiers. It is important, also from an ethical perspective, that data on quality is made available to the public, to media, to service providers, and most importantly, to policy-makers. These target groups need an easily accessible tool for analyzing and visualizing quality indicators that reflect the impact of policy decision in comparison with neighboring Nordic countries. A joint Nordic effort to standardize reporting of performance and outcome indicators and make these publicly available will have the potential to stimulate collaborative research, quality improvement in screening and management of screen-positives, and ultimately translate into improved health outcomes.