

Submission to UICC of Nordic Collaborative Initiatives - UICC Conference 2018

NORDCAN

Fra: webmaster@uicc.org [mailto:webmaster@uicc.org] På vegne af UICC Capacity Building Team

Sendt: 21. februar 2018 13:17

Til: Hans H. Storm <hans@CANCER.DK>

Emne: Form submission from: Call for Collaborative initiatives

Submitted on Wednesday, February 21, 2018 - 13:16

Submitted values are:

Name of your organisation: Danish Cancer Society Are you a UICC member? Yes In which country are you based? Denmark Name/Title of the collaborative initiative: NORDCAN – Cancer statistics for the Nordic countries Please list the names of all countries where your initiative has been implemented:

Denmark, Norway, Sweden, Finland, Iceland, Faero Isles, Greenland, WHO- IARC France copied in Italy World wide users When did this initiative begin? (Month, Year): October 1997 Is this initiative ongoing? Yes Summary of initiative:

NORDCAN is a database of cancer statistics for the Nordic countries: Denmark, Finland, Iceland, Norway, Sweden, Faroe Islands and Greenland. Initially in 1997 it was floppy disk based with data from the 5 Nordic countries forming the Association of Nordic Cancer Registries. Supported by the Nordic Cancer Union the tool was web based and expanded in 2002.

The aim was to have a sound easily available comprehensive statistical and graphical tool with comparable data for situation analysis and benchmarking between the included countries for the purpose of cancer control activities.

The tool is aimed at media and the general population by presenting regularly updated summary data, and the Medical profession and researchers with options to more in-depth analysis.

You can find information on new cancer cases (incidence), cancer mortality, number of persons living with a cancer diagnosis (prevalence), cancer survival, predictions both short and long term and link to animated trend maps on both incidence and mortality. The various statistical information is freely available in tables and figures to use for more than 50 cancer entities.

We deliver cancer statistics for long time periods, for incidence a series that cover more than 70 years, from the beginning of the first Cancer Registry in 1943 to the latest year available. The population-based data that you can find in NORDCAN, are thus more recent than in most other countries in the World, and we update the database each year.

Tabulated data are put to your disposal by the Association of Nordic Cancer Registries (ANCR) and data are delivered from each national Cancer Registry and Cause of Death registry. Population registers makes it possible to follow each cancer patient for death and emigration when we calculate prevalence and relative survival.

Partner organisations:

Danish Cancer society, initiator hosting secretariat, cleaning and preparing data, advising software Development. hosting advisory group International Agency for Research on Cancer, software development and analysis.

Danish Cancer Registry - national Health data authority, Cancer Registry of Norway, National Swedish Cancer Registry -Socialstyrelsen, Finnish Cancer

Registry- Finnish Cancer Society, Icelandic Cancer Registry - Icelandic cancer society, Health authorities for Greenland and for Faero Isles all providing Incidence and mortality data - and participating in the NORDCAN Group.

Nordic Cancer Union - Funding Agency, and also suggesting specific analysis

Objectives:

The aim was to have a sound easily available comprehensive statistical and graphical tool with comparable data for situation analysis and benchmarking between the included countries for the purpose of cancer control activities.

The tool is aimed at media and the general population by presenting regularly updated summary data, and the Medical profession and researchers with options to more in-depth analysis.

The measurable objective is the use and publication of the data. This can be measured by user statistics and published peer reviewed papers.

Impact:

Since 2007 29 published and peer reviewed studies have used NORDCAN as the only source of data, and another 46 peer reviewed papers included NORDCAN in their analysis. To this adds the use of the data in the biannual course in cancer epidemiology in the Nordic countries and uses in courses and training World wide

The data has been used in the formation of cancer control plans in Denmark and the 5 year updates. The Cancer societies of Denmark and Finland updates its cancer information to the public automatically from the software whereas the other Nordic cancer societies make reference to the Tool in their information and lobbying services.

The software has been exported to present Italian cancer data

User statistics for 2017 show 20429 visitors visiting 33773, or 56 visitors per day with 93 visits. 205480 page views and in total 591627 hits during the year and 1621 per day. Main countries using the Tool are ranked: Denmark, Finland, Sweden, USA, Norway. UK, Germany, Estonia, Iceland and 25% from other countris in Europe but also India, Australiaand South America.

Innovation: The software has set a standard for presentation of cancer incidence and mortality data. Too fancy business Graphics are avoided to increase the clarity. The selection for graphical output is guided to avoid overloading and all measures are clearly explained to the user.

Replicability: The software with all facilities has been copied in Italy and by the IARC for presenting mortality data. The basis is the internationally agreed high quality population based cancer registry data, so if such data as well as population data is available it can be implemented.

resourcing: The build of the software was primarily done as part of the daily activties in both the IARC and the Danish Cancer Society. Specific project grants for survival, predictions and animated maps supported the implementation of these and teh cancer registries provided the data as part of their normal activities. Running the NORDCAN Group and updating is at present 35500 € per year. The special grants that all lead to numerous major publications amount to app. 3 mie DKK. The revenue of the existing software can only be measured in saved staff time for descriptive epidemiology i.e. where analysing data and creating a graph could take weeks it is now a matter of minutes.

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Nordic Summerschool in Cancer Epidemiology

-----Oprindeligt meddelelse-----

Fra: webmaster@uicc.org [mailto:webmaster@uicc.org] På vegne af UICC Capacity Building Team

Sendt: 22. februar 2018 14:11

Til: Hans H. Storm <hans@CANCER.DK>

Emne: Form submission from: Call for Collaborative initiatives

Submitted on Thursday, February 22, 2018 - 14:11

Submitted values are:

Name of your organisation: Danish Cancer Society Are you a UICC member? Yes In which country are you based? Denmark Name/Title of the collaborative initiative: Nordic Summerschool in Cancer Epidemiology Please list the names of all countries where your initiative has been implemented: Nordic Cancer Union - Denmark, Sweden, Norway, Finland, Iceland, Faero Isles When did this initiative begin? (Month, Year): august 1991 Is this initiative ongoing? Yes Summary of initiative:

Course and Research Projects for Students in Medicine, Statistics, Biology, Nursing and Public Health.

The Association of the Nordic Cancer Registries (ANCR) holds a summer course in cancer epidemiology every second year. The Nordic Cancer Union (NCU) and the National Cancer Societies in the Nordic countries sponsor the Nordic Summer School in Cancer Epidemiology.

The Nordic Summer School is open to 25 Nordic pre graduate university students in medicine, statistics, biology, nursing and public health. PhD students and Pos Docs without experience in epidemiology and foreign students on long-term exchange or study affiliated with a Nordic cancer research institute may also qualify for the course.

The Nordic Summer School consists of 3 phases:

Phase 1: 2 weeks in August in Copenhagen, which will introduce epidemiology in general, and cancer epidemiology in particular.

Phase 2: During the practical phase, which will take place two working months before January the following year, the students will carry out projects at the national cancer registries or research centres.

Phase 3: In January/February at a prolonged weekend in Virrat, Finland where the participants will present the results of their projects under guidance of tutors. The University of Tampere in Finland hosts this course.

There is no registration or tuition fee. All travel expenses and the Nordic Summer School from a NCU grant will cover accommodation at a low-priced hotel (double room) during phase 1 and 3.

The overall aim is to attract young researchers to the field of cancer and public Health, and to give those chosen Laboratory research sufficient knowledge and skills to place their research in the context of public Health.

Partner organisations:

Nordic Cancer Union - funder and co-host.

Association of Nordic Cancer Registries - program owner and host.

National and regional Cancer Registries in Denmark, Sweden, Norway, Finland and Iceland as well as cancer research centre and universities in the Nordic countries, providing both teachers and tutors for the course elements and for the practical project phase.

Tampere University in Finland – host phase 3 and provide credits.

Objectives: The aim of is on a continuous basis to attract young generations into the research field cancer and public Health. This entail understanding cancer diseases, the epidemiology of cancer, risk factors and methods to analyse, interpret data and report data both to a scientific and a lay audience. It also acts as a recruiting platform and thus both completion of the course, results from the practical phase, later engagement in cancer research and employment at a cancer research institute/Cancer registry/Cancer Society was set as measurable objectives. In addition, stimulation of cross border collaboration in research creating and maintaining networks between participants, tutors and host organisations was an objective.

Impact: After the 11 th summer school impact assessment was done by searching PubMed for papers authored by the app. 275 participants in the course from 1991-2013. In addition, a survey was mailed out to those where a valid e-mail address existed to explore if they had pursued a carrier in research. Over

2338 peer-reviewed publications had emerged from 173 former students. Many of the current research department heads and senior researchers at the cancer registries or cancer research centres in the Nordic countries had this course as their initial and basic training and are involved in international research Projects.

Innovation: Teaching cancer epidemiology is done in many settings. The novelty of this course is the main target audience is pre-graduate students or inexperienced new researchers e.g. young physicians in the beginning of their career. In addition the 2-month practical phase doing a proper study in an established research Group with hands on methods, data leading to a third phase with training in presenting, and publishing is novel. This is praised repeatedly in the student assessment of the courses over time. In addition, the grant from NGO's is appreciated.

Replicability: Wherever there is a cancer registry Network, and cancer research institutes willing to host students as a strategic Investment in the future of cancer research, skills to run a similar course is present. With the example taken from the Nordic Cancer Union other cancer societies may consider co-fund courses as this as part of the research funding they support.

resourcing: The NCU grant to run this course for 25 Nordic students, including accommodation, meals, teaching fees and salary to support staff amounts to 95000€ per course. The revenue of this Investment can be seen in the direct output and the number of students ending in cancer research and public Health.

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