Minutes from the NORDCAN meeting 4-5 March 2009

Place: Danish Cancer Society, Copenhagen
Participants: Jacques Ferlay, Elínborg Ólafsdóttir, Eero Pukkala, Freddie Bray, Åsa Klint, Marianne Lundkjær Gjerstorff, Hans Storm, Niels Christensen, Gerda Engholm, Anne Mette Kejs
Apologies: Jóanis Erik Køtlum

Agenda
Points from the forwarded agenda are shown in italics.

1. Minutes from last meeting 4 September 2008. The minutes can be found at the homepage www.cancer.dk/nordcansecretariat. The minutes were approved.

2. From the secretariat.
   a. The web-version was updated to version 3.3 10/11 2008.
   b. Graphics have been renewed in the English, Danish and Finnish versions, while this is not done yet for the Icelandic, Norwegian and Swedish versions. Jacques will make national test-versions after receiving the last translations Approval of graphics in these test-versions by e-mail from IS, NO and SE is needed before updating the on-line version. Jacques wants this to be done before updating to the next version.

   c. Data delivered.

      All have now been received. The data from FO is not yet processed and Niels is waiting for the final approval of the Norwegian data Data for the March update will be delivered to Jacques as soon as possible and within 3-4 weeks.

   d. Delivery of old data in ICDO-3 from Denmark, Finland, and Norway.
      Conversion back in time has been checked for Finland where some changes have been observed for breast cancer, soft tissue and stomach. According to Risto the new codes are the correct. In the Danish data some errors in the conversion from ICD7 before 1978 has been found for leukemia and for lung
cancer. We have yet some discussions to make in Denmark about coding of lymphomas, chronic myeloproliferative disorders and myelodysplastic syndromes. We expect some checks to be made and discussed when the Norwegian data arrives.

Chronic myeloproliferative disorders and myelodysplastic syndromes are not to be included as cancers in NORDCAN. We have compared the number of incident cancers in the entities back in between the old deliveries and the new deliveries in ICDO-3 time from Denmark, Finland and Norway and now only minor differences are found.

e. Error and warning lists for each country.
In the process of conversion of data from each country, Niels has uploaded the error and warning lists to the ftp-server and has sent an e-mail to the person responsible for data in each country for correction and acceptance.

3. News from each of the countries
a. FI: Following a NORDCAN press release in January 2009, a “How to use NORDCAN” interactive workshop was held primarily ad dressing researchers, ministries, professors and public health researchers. About 80 people attended the workshop. Eero reported intensive use of the new graphic facilities.

b. SE: Åsa reported a NORDCAN presentation held for the General Director of the national board of Health and Welfare (Socialstyrelsen). The GD was very impressed by NORDCAN. The StatFact sheet has been of high value in handling questions from journalists.

c. DK: NORDCAN has been promoted in the National Board of Health and the Ministry of Health and Prevention. Both the Ministry and the Board have been very impressed by NORDCAN and are expected to be using NORDCAN in the future. The web version of NORDCAN is frequently used when answering questions from journalists, researchers and students and is used for supplying statistics for each cancer site at the homepage of the Danish Cancer Society http://www.cancer.dk/Alt+om+kraeft/kraeftsygdomme/

d. IC: NORDCAN has been presented inhouse in the Icelandic Cancer Society, in epidemiology teaching and at the pathological department and is used for answering questions. Laufey would like to have the average age included in the Cancer Stat Fact sheets. To be addressed under item 8g).

e. NO: There has been a lot of positive response on NORDCAN from the researchers. NORDCAN will continuously be promoted in NO. The Cancer Registry is satisfied with NORDCAN. Trend analyses of colon cancer versus rectum cancer have been performed using NORDCAN. Also frailty analysis of Hodgkin’s lymphoma has been using data from NORDCAN.
4. **New categories in NORDCAN?**

   a. Some have asked for subdivisions of pharynx as in CI5 version IX (Tonsil C09), Other oropharynx (C10), Nasopharynx (C11), Hypopharynx (C12-13), Pharynx unspecified (C14). Divisions of leukemia with categories CLL, CML, ALL, AML has also been asked for. These divisions can be viewed back in time for Denmark (back to 1978) and Iceland (from start) in CI Adds detailed, but not for the other countries. The secretariat is willing to make some graphs of ASR(W) for comparability check back in time for all countries.

   b. Division of morphologies as I CI5 version IX. For Denmark this will only be possible back to 1978, but with all countries having recoded to ICDO-3 back in time it would be possible to tabulate for all countries to view the comparability. If this is possible, should we make a new database (just in English)?

   The group agreed that subdivision of categories should be done with caution and preferable not at all. However it could be beneficial to copy the CI5 entities.

   Hans suggested making a wish list for new entities and separate detailed databases before our next meeting and then discuss the need/demand for subdivisions/database. Please send wishes to Gerda 2 months before our next meeting.

5. **Prediction. Look at Jacques’ mail from 24/2**

   Jacques presented his work on 2 methods of prediction. Short term (5 years) and long term prediction (up till 25 years).

   The group was very impressed with the work and agreed that it should be included later in web-NORDCAN.

   The short term prediction is of high political interest and the long term prediction (max 15 years) will be of high interest in cancer prevention.

   Jacques will draft a proposal for collaboration on the project and deliver www-link and password for a trial version when ready.

6. **Update of PC-version, 35-year time series 1972-2006**

   When the web-NORDCAN has been updated in March 2009, the PC version will be updated for the last time. The secretariat needs population numbers for the counties for the last years.

   The NORDCAN-group should make a wish list of features from the PC-NORDCAN to be implemented in web-NORDCAN. Two wishes have already been brought up: 1)
creating new diagnosis groups as sums of existing entities
2) division into regions. Points to the wish list should be sent to Gerda. Gerda will send a reminder for input to the wish list approximately 2 months before the next meeting.

7. **New graphics in NORDCAN.** Any wishes for changes or developments? Gerda would like to have a horizontal option for the cohort line charts (as in the PC-version) to be able to view them better on the PC. Fixed colors for colors for countries have been wished.

Fixed colors for countries is difficult to implement because of the high number of choices with combinations by countries, data types, sex, and diagnoses for lines. Jacques will take a quick look at the colors again.

8. **Revisions of texts and sub-menus**
   a. **Cancer dictionary, sorted by ICD-10**
      Jacques will make the page dynamic, i.e. make it possible to choose sorting by ICD-7 or ICD10.

   b. **CI-interval for EAPC.**
      The explaining text in Glossary terms could be “The approximate 95% confidence interval for the true EAPC is based on the upper and lower confidence limits obtained in the simple regression model of the log of the rates or numbers.” The statistical calculations can be obtained at: http://srab.cancer.gov/joinpoint/aapc.html. It will only be included in the tables of standardized rates by year where the 95%CI will be added an extra row below the line with EAPC.
      Programming of the 95% CI will be made by Jacques following a suggestion from Freddy.

   c. **Version history, overview of years covered for versions back in time.**
      The decision made at the meeting in September 2008 was:
      “It should contain an overview of the included new years of data and the corrections in the current version. Previous updates and correction should be put as links, and should contain the table of years available. It should always be obvious which version is the current.”
      This decision was annulled.

   d. **References, any new?**
      New references should be e-mailed to Gerda within 2 weeks; a new reference list should be added. The 3 headlines should thus be: “Studies using NORDCAN as a primary data source”, “Other studies using NORDCAN”, and “Homepages using NORDCAN”.
      The reference lists are difficult to read. Format should be as in pubmed, sorting should be with the newest first, a blank line should be included between references.
      The reference lists should be updated at least twice a year (when the NORDCAN data is updated), but it is possible to have a reference added at anytime by e-mailing it to Jacques.
e. In Tables, Age-specific rates, we would also like to make it possible to choose to show numbers for the age groups and not just rates.

f. In the menu for incidence and mortality graphs “Trends by age” should be changed to “Time trends by age” and for prevalence graphs “Line chart: trends” should be changed to “Line chart: time trends”. Translations to each language should be sent to Jacques.

g. Laufey had asked us to include mean or median age in the Cancer Stat Fact Sheets, but we decided that it was too complicated to calculate based on the tabulated data delivered to Jacques.

h. In the Cancer Stat Fact Sheet there should be hanging indentation for incidence, mortality and prevalence to clarify the period for which the figures are calculated.

i. Eero suggested to remove the line “proportion of all cancers (%)” in the Cancer Stat Fact Sheets due to incomparability of the non-melanoma skin cancer group in Denmark compared to the other countries. Instead we decided to not to include basal cell carcinomas in “Skin, non-melanoma” from 1978 and onwards in the Danish data and then to keep both “proportion lines” in the Cancer Stat Fact Sheets. Jacques will include the category “All cancers” in the diagnosis choice for the Cancer Stat Fact Sheets and will explore the consequences of an “all cancers” category for the other menu points.

j. Graphics in the Cancer Stat Fact Sheets: Colors should be standardized to blue for men and red for women (The secretariat suggests green/orange since this is easier to separate when printed in black/white). Titles in the English version should be “Age standardised rates per 100 000 (W) over time” and “Age specific rates per 100 000”.

9. **Download requests and password.**

   There has been tree requests for downloads from NORDCAN during the past month. Michael Hartmann, Sweden/Singapore comparison of prostate cancer incidence and mortality; Sue Moss, UK, Trends in breast cancer incidence and mortality and screening activity, and Yang Qian, a colleague of Hartman in Singapore wants to study colorectal cancer in Sweden and Singapore. Since then another colleague, Teo Shu Mei, has asked to study cervix cancer in Sweden and Singapore. The password should be valid for 3 months only.

   In the future it would be preferred to have two different passwords, one changing for download requests and a more permanent one for use in the NORDCAN group: NORDCAN spelled backwards.

   The purpose of password for download requests is mainly to get an overview of further user needs in NORDCAN.

10. **Eurocim and further check of comparability between countries (i.e. the other group).**

    The Eurocim project is on hold for the moment and has to be re-evaluated.

11. **Papers:**
a. General NORDCAN paper. A manuscript has just been distributed with this agenda.
The paper should be published in Acta Oncologica and with acceptance from the editor with duplicate publications in national medical bulletins.
The authorship should be as in NORDCAN.
Freddie suggested that the paper should have a more clearly scientific structure and we discussed using screen dumps of menus instead of text tables.

b. Papers on specific sites.
The general NORDCAN paper should be published first followed by one example of a specific cancer site as a possible. Maybe this could be an assignment for a summer school student.
The list of specific sites is to be discussed at the next meeting, however without the deadline.

12. Time plan for future updates:
Mortality data for 2007 in DK, SE and NO should be ready for the NORDCAN update in September 2009 as well as incidence data for Denmark 2007.

13. Next meeting.
Should be following the ANCR meeting in Stockholm in 4 September 2009 in the afternoon. Åsa will arrange meeting facilities.