

9.1

Revision of the statutes for the Nordic Cancer union



To the Board of the Nordic Cancer Union

From Ragnheiður Haraldsdóttir

Reykjavík, February 8th 2016

The Nordic Cancer Union has decided to revise its statutes.

For those interested in how the current document has developed an attachment is included with information that was on the table at the meeting of a NCU workshop on the secretariat in Arlanda in November 2015.

Also enclosed are the statutes that RH and Elizabeth Hjorth have been working on and some proposed changes.

It is proposed that the board of the NCU discusses the proposed changes and provides guidelines for further work based on the current document,- with the time frame in mind that this could be adopted at a meeting of the NCU in Reykjavik May 30th 2016.

Role of the board of the NCU and revisions of the statutes

To members of the working group on NCU leadership and functions

From Ragnheiður Haraldsdóttir

November 19th 2015

The Board of the NCU has decided to review the statutes of the NCU. The time frame that has been proposed is to present and discuss a draft at the NCU Board meeting in Oslo in February 19th 2016, and eventually to call a meeting of the committee of representatives in May 2016 for its contemplation and perhaps an adoption of the new statutes. The perceived need and reason for this revision is at least in part the fact that the work of the NCU has undergone some changes and the statutes are not adhered to closely.

The discussions of the working group on the functions of the secretariat and of the role of the chairman will indeed provide good bases for the revision. The current chairman and the legal advisor for the next country at the helm according to the current statutes, Ragnheiður Haraldsdóttir and Elizabeth Hjorth, have already organized two meetings to initiate the revision. The aim is to submit the draft revisions to the Board of the NCU well in advance for the February meeting, and to ensure that the board has ample time at that meeting for the deliberations.

Some of the items that might come under consideration are highlighted here, while others will become clear as we progress in the work. Some of the comments might be considered irrelevant by the NCU. Maybe more changes that will be considered necessary in our revisions will stem from the discussions of the working group,

Following are the current statutes with some pertinent questions that might be helpful for the working group.

Statutes of the Nordic Cancer Union § 1 Preamble

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

The overall strategies and priorities for NCU are stipulated for three-year periods by a Committee of Representatives comprising the chairmen of the member organisations.

Comment [RH1]: Should coincide with the chairmanship?

§ 2 Aim and strategy

The aim of the NCU is

- collaboration to improve knowledge and understanding of cancer diseases, effective prevention and health promotion, results of cancer treatment and rehabilitation; and to enhance their effective application in the Nordic area.
- to fund Nordic research and strategic projects of high standards within the field of cancer

§ 3 Committee of Representatives

1. The Committee of Representatives comprises the chairmen of the member organisations.

2. The Committee of Representatives meets every third **year** in the autumn.

Comment [RH2]: The practice has been more often, in my experience. They often attend a spring meeting...

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

4. The tasks of the Committee of Representatives are to

- approve the strategic plan for the coming three-year period based on the recommendation from the Secretaries-General
- approve the report and evaluation of the NCU activities in the past three-year period
- approve the chairmanship for the coming three-year period
- perform changes of statutes
- approve observer members

5. A scientific conference may be held in connection with the meeting for the Committee of Representatives. **The** main themes of the conference are decided by the Secretaries-General and include discussions of actual, principled cancer relevant issues, long-term strategies and evaluation of activities.

Comment [RH3]: We have been doing this although irregularly at the regular board meetings I think

Chairmen and Secretaries-General of the NCU members and invited guests participate, including representatives of ANCR – Association of the Nordic Cancer Registries.

6. An **informal** meeting is held in the middle of the period of the chairmanship for the chairmen and Secretaries-General with the purpose of exchanging experiences, and discussing on-going and actual cancer related topics.

Comment [RH4]: Why is this one less formal?

§ 4 Chairmanship

1. The chairmanship is held alternately by the members for a 3-year period taking effect from the start of a calendar **year**.

Comment [RH5]: As I understand it, this will be discussed thoroughly in our working group.

2. The chairmanship of the NCU is responsible for the Union's secretariat function during the mandate period in relation to general matters and the scientific committee²¹. The responsibility of the secretariat of advisory committees including a scientific committee may by specific agreement be transferred to another member organisation.

Comment [RH6]: Could this maybe be interpreted as the contract should be re-established for each period? Have not been done to the best of my knowledge, but maybe good...

3. The society holding the NCU chairmanship co-ordinates collaboration between the Secretaries-General.

4. The chairmanship is responsible for planning a meeting for the Committee of Representatives during the late autumn of the last year of the chairmanship period, including preparation of an activity and evaluation report and for the chairman period.

5. The Chairmanship is responsible for planning an informal ²²meeting to be held in the middle of the period of the chairmanship for the chairmen and Secretaries-General with the purpose of exchanging experiences, and discussing on-going and actual cancer related topics,

§ 5 Board

1. The NCU is governed by a Board comprising the Secretaries-General of the member organizations of NCU.

2. The Board has 3–4 annual meetings, usually in December/January May/June and September/October.

Specialists/staff members of the member organizations may participate and/or represent the members.

Main topics of the meetings include:

- All meetings: exchanges of experiences, decisions on strategic projects
- December/January meeting: approval of annual budget including allocation between strategic and scientific projects and report from the scientific committee
- May/June meeting: approval of accounts and annual report for previous year
-

Comment [RH7]: Strategic at all meetings?

Comment [RH8]: We are in the process of drafting a new paper regarding this, might mean changes

3. The Board makes decisions concerning grants for strategic projects.

4. The Board decides after recommendations from the scientific committee grants for scientific projects.

5. Board may decide to establish committees and appoint committee members.

Comment [RH9]: For specific purposes in line with the current strategy. Are they always ad hoc?

6. Decisions of the Board are taken by a simple majority of the Board members present. In the event of a tied vote, the NCU Chairman has a second, casting vote.

7. The minutes of the Board meeting are signed by the NCU Secretaries-General.

Comment [RH10]: hnnnnnnnn

8. NCU contributes to the costs of the secretariat as decided by the Board.

§ 6 Scientific committee

1. The scientific committee comprises one member with scientific competence from each member country appointed by the NCU Board after recommendations from the national cancer societies.

2. The tasks of the committee are:

- to assess scientific grant applications, secure high scientific quality and formulate recommendations regarding the applications to the Secretaries-General for their decisions on grants
- to give consultation concerning strategic projects regarding research to the Secretaries-General for their decisions on grants
- to evaluate funded research and follow-up on the application of the results in the Nordic countries

3. The scientific committee is invited to an annual meeting and to the meeting for the Committee of Representatives held every third year.

Comment [RH11]: should we change this?

§ 7 Finances

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

2. The annual budget, cost allocation between the members and balancing of the accounts are approved by the Board.

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

4. Decisions regarding the apportionment of any overheads not governed by the provisions of the statutes are taken by the Board.

§ 8 Signatories

1. The chairman of NCU and the Secretary-General of another society or two other Board members authorised by the Board may sign jointly on behalf of the NCU.

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

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

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

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

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

Statutes approved by the NCU Board on 10. December 2012 and will be effective 1 January 2013.

Statutes of the Nordic Cancer Union some proposals

§ 1 Preamble

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

The overall strategies and priorities for NCU are stipulated for three-year periods by a Committee of Representatives comprising the chairmen of the member organisations and should coincide with a chairmanship of a member country.

§ 2 Aim and strategy

The aim of the NCU is

- collaboration to improve knowledge and understanding of cancer diseases, effective prevention and health promotion, results of cancer treatment and rehabilitation; and to enhance their the effective application of in the Nordic area.
- to fund Nordic research and strategic projects of high standards within the field of cancer

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2. The Committee of Representatives meets every third year in the autumn at the end of a chairmanship and additionally as deemed necessary.

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4. The tasks of the Committee of Representatives are to

- approve the strategic plan for the coming three-year period based on the recommendation from the Secretaries-General
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5. A scientific conference may be held in connection with the meeting for the Committee of Representatives. The main themes of the conference are decided by the Secretaries-General and include discussions of actual, principled cancer relevant issues, long-term strategies and evaluation of activities.

Chairmen and Secretaries-General of the NCU members and invited guests participate, including

representatives of ANCR – Association of the Nordic Cancer Registries.

6. An informal meeting is held in the middle of the period of the chairmanship for the chairmen and Secretaries-General with the purpose of exchanging experiences, and discussing on-going and actual cancer related topics.

Comment [RH1]: Why is this one less formal?

§ 4 Chairmanship

1. The chairmanship is held alternately by the members for a 3-year period taking effect from the start of a calendar year.

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

3. The society holding the NCU chairmanship co-ordinates collaboration between the Secretaries-General and is:

~~is responsible for planning the a meetings for the Committee of Representatives during the three year period, late autumn of the last year of the chairmanship period, including preparation of an activity and evaluation report for the chairman period.~~

5. The Chairmanship is responsible for planning an informal ??meeting to be held in the middle of the period of the chairmanship for the chairmen and Secretaries-General with the purpose of exchanging experiences, and discussing on-going and actual cancer related topics,

Comment [RH2]: Why?

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Comment [RH3]: Strategic at all meetings? We decided a tone meeting to have this only in February

Comment [RH4]: We are in the process of drafting a new paper regarding this, might mean changes

Comment [RH5]: Annual report could be sooner?

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Comment [RH6]: For specific purposes in line with the current strategy. Are they always ad hoc?

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7. The minutes of the Board meeting are signed by the NCU Secretaries-General.

Comment [RH7]: Hmmmmm delete?

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3. The scientific committee or its chairman is invited to an annual meeting when their recommendations are discussed, and to the meeting for the Committee of Representatives held every third year.

Comment [RH8]: should we change this?

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|

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

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

Statutes approved by the NCU Board on 10. December 2012 and will be effective 1 January 2013.

NCUs administrativa funktioner / sekretariat

Bakgrund

En arbetsgrupp har bildats för att identifiera och genomlysna olika alternativ för de administrativa funktionerna i NCU. Arbetsgruppen hade en endags-workshop 23 november 2015 på Clarion, Arlanda Airport. Bifogat finner ni mötesanteckningar. En muntlig rapport lämnades på styrelsens telefonkonferens 2 december.

Arbetsprocess framåt

- Arbetsgruppen har nästa möte i Köpenhamn den 17 mars kl 10.00
- Slutförslag presenteras på the committee of representatives meeting 30 maj 2016

Att diskutera och ta ställning till på styrelsemötet

Fastställa den fortsatta inriktningen och arbetsprocessen för att kunna lägga fram förslag till beslut som kan träda i kraft från och med att Danmark övertar ordförandeskapet 2018.

Minnesanteckningar

Arbetsgrupp NCUs administrativa funktioner

Datum: 2015-11-23

Plats: Clarion Hotel Arlanda Airport

Deltagare: Elizabeth Hjorth, Jákup Olsen, Ole Alexander Opdalshei,
Ragnheiður Haraldsdóttir, Sakari Karjalainen, Sanna Wärn, Stefan Bergh

Målet med mötet var att

- identifiera och genomlysna olika alternativ för de administrativa funktionerna.
- fastställa den fortsatta arbetsprocessen för att kunna lägga fram förslag till beslut som kan träda i kraft från och med att Danmark övertar ordförandeskapet 2018.

Mötet genomfördes som en endags-workshop.

1. Uppdraget

Utifrån NCUs stadgar och andra styrande dokument gick vi igenom uppdraget för

- NCU övergripande
- styrelsen
- ordförande
- Scientific Committee

Uppdrag för NCUs administrativa funktion (Sammanställning av gruppens synpunkter)

- Planera och genomföra NCUs möten
- Ge stöd till NCUs ordförande
- Hantera all administration kopplad till NCUs verksamhet inkl ekonomi
- Bereda underlag kring NCUs olika områden:
- Forskning
- Strategiska projekt
- Omvärldsbevakning
- Kommunikation

Kommentarer:

- Sakari lyfte att många ärenden till NCU rör "utrikespolitik" / sådant som ligger utanför Norden
- Stefan påtalade att NCU bör bevaka så att det inte sker en "mission drift"
- Ole Alexander menade att NCU i första hand är ett nätverk för att utbyta idéer vilket bör göra att administrativa uppgifter borde kunna minimeras. Ta fram en enkät för medlemsländerna om vad ambitionen med NCU är → diskussionsunderlag.
- Ragna ser NCU som en möjlighet att tala med en, stark röst
- Jåcup tyckte att NCU borde vara mer proaktiva

Kommentarerna noteras men hanteras i annat forum

2. Administrativ förmåga

Vad vill vi ska utmärka NCUs administrativa förmåga?
(Postit-övning. Svar sammanställt i urval)

| | | |
|--|--|---|
| Transparens | Tydlighet | Resurseffektivitet |
| Resurseffektiv | Proaktiv | God kommunikation |
| Mötesförberedelser; effektivt, kvalitet, tydlighet | Tillgänglighet | Kommunikativ- webb & mail |
| Välorganiserade möten & documentation | Öppen för idéer, förmåga att implementera nya idéer | Strategiskt förhållningssätt |
| God förmåga att leda möten | Framförhållning | Kvalitet |
| Tydlig | Kommunicera aktivt med/ involvera medlemmarna | Stöd till ordförande så att hon/ han kan fokusera på strategiska frågor |
| Snabb återkoppling | Goda språkkunskaper | "hög lägstanivå" |

3. Vad vill vi utveckla/ förändra/ förbättra

| | |
|---|--|
| Tillit | Ekonomi - för mycket tid till diskussioner - Mer kontinuitet - Bättre dokumentation |
| Kortare mötesanteckningar | Missiv/ Draft/ Coverletter till "alla" mötespunkter |
| Förtydliga huvuduppdraget och hur detta följs upp/What is the core business? | Identifiera och bli/ vara bra på kärnuppgifterna |
| Bättre kontinuitet för ekonomin | Ta fram arbetsordning för administrativ funktion |

4. Samtal utifrån olika scenarion

a. Administrativ funktion flyttar med det roterande ordförandeskapet

| Positivt | Negativt |
|--|--|
| Starkt presidium | Särbart när presidiet flyttar; dålig kontinuitet. Uppfinna hjulet igen & igen |
| Resurseffektivt- ordföranden som <u>riktig</u> ledare | Kontinuitet kan bli svår |
| Närhet mellan ordförande & sekretariat | Svårt att säkra kvalitet när sekretariatet flyttar |
| Stabilitet | Dålig struktur på lång sikt |
| Korta vägar för att hantera administrativa frågor | Kan bli tung administrativ uppgift för vissa organisationer |
| | Risk för sämre stabilitet, kontinuitet & kvalitet |

- b. Samlad administrativ funktion (inkl scientific admin) permanent i ett land, roterande ordförandeskap

| Positivt | Negativt |
|--|---|
| Stabilitet | Mindre demokratiskt |
| Professionalism | Risk för "lack of passion" |
| Kontinuitet | Dyrt |
| Ordföranden har ett professionellt & erfaret sekretariat | Problem kan bli svåra att lösa när man inte skiftar sekretariat |
| Säkrar "good governance" | Avståndet kan bli ett problem |
| Kvalitet | Kan ha negativ inverkan på medlemmarnas involvering |
| Smidigare överlämningar då ordförandeskapet roterar | Komplicerad dialog & effektivitet mellan ordförande & sekretariatet |
| | Kommunikation mellan ordförande & sekretariat på mail |
| | Ordföranden är mer utan stöd |

- c. Vissa administrativa funktioner i permanent land/ annat administrativt roterande med roterande ordförandeskap

| Positivt | Negativt |
|---|---|
| Möjlighet att bygga en klassisk organisationsstruktur | Styrelsen behöver med vissa mellanrum ta ställning till |
| Ger ordförande stöd | Otydligt |
| Flexibelt? | "vem har ansvar för vad?" |
| Specialisering | För komplext |
| Ordförande kan lägga fokus på "rätt saker" | Otydligt ansvar |
| Säkrar kvalitet på viktiga områden | Svårt att styra |
| Möjligen fler som känner större ansvar att bidra till NCUs uppgifter/ uppdrag | "Tävlan" mellan sekretariaten |
| Ger möjlighet till involvering & ansvar från flera | Samordning kan bli svår |
| Kontinuitet för basala funktioner | Hur säkerställer man gemensam bild av NCU? |

5. Övrigt

Arbetsgruppen var enig om att ordförandeskapet bör rotera mellan medlemsländerna.

Att diskutera i annat sammanhang:

- Hur mycket vill alla bidra? (Ragna)
- Vill vi använda NCU till advocacy tillsammans och i så fall hur? (Jåkup)

6. Arbetsprocess framåt

- Skriftlig dokumentation från detta möte skickas till alla deltagare.
- Telefonmöte: muntlig rapport, 2 december
- Skriftlig lägesrapport: Styrelsemöte 19 februari
- Möte arbetsgrupp i Köpenhamn: 17 mars kl 10.00 - ?
- Slutförslag presenteras: Generalförsamling 27 maj

To the board of the NCU from Ragnheiður Haraldsdóttir

Some Ideas proposed by Sakari Karjalainen regarding the meeting in Finland in August/September to be discussed at the meeting in Oslo February 19th 2016

Wednesday, August 31st

ANCR Conference (open also for the NCU Board Members to participate)

The joint social programme in the evening (ANCR and NCU)

Thursday, August 1st

08.30 – 09.30 The joint meeting of the NCU and ANCR Boards

09.30 – 12.30 The joint symposium of the NCU and ANCR Boards

12.30 – 13.30 Joint lunch

13.30 – 16.00 The Meeting of the NCU Board

Joint Seminar of the ANCR Board and NCU Board from 8.30 to ??(incl. lunch)

- Topic: **Cancer burden in the Nordic countries**
- Opening speeches á 10 minutes (Ragna and the Chair of the ANCR Board)
- Cancer incidence, prevalence and mortality (one of the Directors of Cancer Registries)
- Cost of cancer (health economist from Finland or from Sweden)
- Do the Nordic governments have a similar approach to tackle with the cancer burden – a comparative analysis of National Cancer Control Plans (an expert from Norway)
- What should the ANCR do to improve cancer control in the Nordic Countries (Hans Storm?)
- What should the NCU do to improve cancer control in the Nordic countries (Ragna, Anne Lise or Leif)

Nordic Cancer Union
Meeting 19/2 2016

UICC policy – who decides?

Following the UICC world cancer leaders' summit the Danish Cancer Society was approached by Professor Frede Olesen, the previous Chairman of the DCS and current Chair of the NCD Alliance in Denmark.

In brief, he was worried by the attitude to the report from a break-out session chaired and reported by Professor Michel Coleman LSHT. Prof Coleman was accused by the UICC CEO Cary Adams for "abuse of his role" "wasting precious time for debate" by "forcing the UICC leadership to commit impromptu to respond to the EU stance on data sharing" i.e. the upcoming at the time problematic privacy regulation in the EU. This message from Cary Adams was passed via his associate Julie Torode, who also passed the message that the UICC withdrew the support to the CONCORD survival project (until today only moral).

The Danish Cancer Society who as many other member organisations (in the ECL) have been active in lobbying for a sensible privacy legislation in EU is worried the UICC find this topic of little relevance and a waste of time. Further as participant in and user of CONCORD results, we are surprised these two activities are inter linked by the UICC office.

For that reason we asked the UICC president Teser Kutluk as well as the Nordic representative Anne Lise Ryel to enlighten us on what happened. Teser replied that the support for CONCORD should be sorted out directly between prof. Coleman and Cary Adams. At the same time Prof Richard Sullivan (UICC board member) who had been contacted by Prof Coleman expressed his concern and surprise by the action from UICC.

Our question is whether the UICC board was heard and agree to the action from Cary Adams. If not, whether it is acceptable, the CEO runs his own agenda without consultation of the elected board members. If the Board was involved we would like to know the arguments for change in support to an international project benchmarking cancer survival world wide, and the arguments for UICC not to take a position on fundamental legislation that potentially could change sharing of data on patients and research based progress in public health and cancer care.

Proposal:

The Danish Cancer Society asks NCU to assist in reaching a satisfactory closure of this by asking UICC for explanation and actions taken to remedy this really unfortunate situation brought upon multiple researchers and research institutions world wide engaged in the Concord project. Further a clarification of the UICC role as policy advocate assisting European members, cancer research and patients is warranted.