

Reykjavík den 17 maj 2017

NCU:s styrelsemöte i Köpenhamn 29 maj 2017

Dagordningskommentarer

Mötesordförande: Ragnheiður Haraldsdóttir

Mötesplats: Kræftens Bekæmpelse, Strandboulevarden 49, Köpenhamn, Danmark.
Mötestid: Kl. 09:30 – 15:30; Kaffe kl. 09:00-09:30, Lunch kl. 12:00 – 13:00.

Inledning

1. **Mötets öppnande.**
2. **Godkännande av dagordning.**
3. **Godkännande av referat.**

Styrelsen får tillfälle att lämna ytterligare synpunkter på referatet från mötet den 27 februari. (Separat utskick).

4. **Översikt över strategiska projekt.**

I enlighet med tidigare beslut presenterar ordförandeskapet en översikt över det ekonomiska läget gällande strategiska projekt. **Bilaga (nr. 1).**

Beslutsfrågor

5. **NORDSCREEN.**

Bilaga (nr. 2)

Application for NCU strategic funds.

Kommentarer

NORDSCREEN är projekt som har för uppgift att etablera interaktiva redskap och ta fram indikatorer för cancerscreening som baseras på liknande konceptplattform som NORDCAN. Vid styrelsemötet i Stockholm den 17 februari i år förelåg det omfattande dokumentation om projektet. Man var enig om att saken krävde noggrannare beredning. NCU:s ordförande och Hans Storm fick i uppdrag att skriva utkast till

svarsbrev till NORDSCREEN. Stefan Lönberg skickade sina reflectioer angående kommenten fraan Hans.

Förslag

Styrelsen tar ställning till föreliggande projektansökan.

6. Forslag til 3-års plan 2018 – 2020.

Baggrund

Kræftens Bekæmpelse overtager NCU formandskabet med virkning fra 1. januar 2018. Den forberedende proces herfor er påbegyndt.

NCU bestyrelsen har tidligere truffet beslutning om NCUs strategi for perioden 2015 – 2018.

Hvert 3. år skal NCU bestyrelsen ifølge NCU statutterne træffe beslutning om en 3-årsplan som udfylder og præciserer fokus/temaområder for den kommende 3-års periode.

De overordnede hovedpunkterne i den gældende NCU strategi er, at NCU arbejder for (citater fra NCU strategi):

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

Kræftens Bekæmpelse foreslår, at

- den tidligere vedtagne overordnede strategi fastholdes og videreføres for 3 – års perioden 2018 – 2020
- der sættes fokus på styrkelse af NCU samarbejdet på et specifikt tema inden for hvert af de 5 hovedområder, og at der lægges vægt på, at temaerne omfatter forhold, som rent faktisk er sammenlignelige i de nordiske lande, og at landene hver især har succesfulde indsatser, som kan medvirke til gensidig inspiration og have reel synergieffekt.

Kræftens Bekæmpelse har på den baggrund udarbejdet vedlagte forslag til specifikke initiativer inden for hvert af de 5 hovedtemaer.

Bilag:

Bilag (nr. 3.) "Proposal for specific initiatives in the period 2018 - 2020 on each of the 5 main topics in NCU strategy plan".

Bilag (nr. 4.) NCU's strategi for perioden 2015 – 2018.

Indstilling til NCU bestyrelsens drøftelse og beslutning:

Kræftens Bekæmpelse foreslår, at NCU bestyrelsen godkender, at

- den tidligere vedtagne overordnede strategi fastholdes og videreføres for 3 – års perioden 2018 – 2020
- der sættes fokus på styrkelse af NCU samarbejdet på et specifikt tema inden for hvert af de 5 hovedområder, hvor der lægges vægt på, at temaerne omfatter forhold, som rent faktisk er sammenlignelige i de nordiske lande, og kan medvirke til gensidig inspiration og have reel synergieffekt
- de i bilaget "Proposal for specific initiatives in the period 2018 - 2020 on each of the 5 main topics in NCU strategy plan" som 3 årsplan for perioden 2018 – 2020.

7. Forslag om strategisk indsats sammen med og økonomisk støtte til Tobacco Free Portfolios/Bronwyn King.

Baggrund

De nordiske lande har gennem mange år haft en stærk og innovativ indsats på folkesundhedsområdet. De nationale kræftforeninger har alle haft aktive og indflydelsesrige roller i en bred vifte af folkesundhedsinitiativer. Det gælder blandt andet inden for tobaksområdet, hvor der er sket markante fremskridt til begrænsning af rygning.

Også i NCU regi har der gennem årene været fælles effektive kampagner mod børns eksponering for tobaksrøg, ligesom der er blevet udvekslet inspiration og erfaringer med rygestop samt erfaringer med en række lovgivningsmæssige og beskatningsmæssige initiativer til at begrænse rygning.

Indsatsen mod tobaksrygning og tobaksindustrien må løbende udvikles og optimeres, så den omfatter både traditionelle og nye vinkler, der kan bidrage til overordnede internationale og nationale mål hen mod en Røgfri Fremtid.

Kræftens Bekæmpelse ønsker at sætte fokus på initiativet Tobacco Free Portfolio, som en mulighed for en 3-årig strategisk NCU indsats gennem økonomisk støtte fra NCU.

Tobacco Free Portfolios

Kræftens Bekæmpelse blev i 2016 opmærksom på det bemærkelsesværdige initiativ *Tobacco Free Portfolios*, som den australske onkolog Dr. Bronwyn King har taget. Bronwyn King har stiftet Tobacco Free Portfolios som sætter fokus på, at indsats mod finansiel støtte til tobaksindustri og investering i tobak er en afgørende, men hidtil vigtig og manglende brik i den globale indsats mod tobak.

Tanken med initiativet *Tobacco Free Portfolios* er at begrænse tilførsel af finansielle resourcer til tobaksindustrien, sådan at industrien på længere sigt vil få vanskeligheder ved at producere og markedsføre sine sundhedsskadelige produkter.

Tobacco Free Portfolios arbejder i Australien, Europa, USA og Canada dedikeret og professionelt med den finansielle sektor for at få denne til at ophøre med investeringer i tobaksindustri, så finanssektoren fremover bakker op om og kommer på linje med internationale konventioner og nationale målsætninger på sundhedsområdet om at begrænse tobakssektoren.

Tobacco Free Portfolios strategi er en målrettet indsats i forhold til de administrerende direktører i store pensionsselskaber i mange lande. Det er en stor og tidskrævende indsats – ikke mindst fordi det primære virkemiddel er personlige og direkte møder på højt plan. Det er forventningen, at den intensive mødeindsats med tiden vil få en ”viral” virkning, sådan at flere og flere selskaber såvel som kunder vil indse det uholdbare i investering i tobak.

Bronwyn King har allerede nu formået at overbevise en lang række administrerende direktører for store pensionskasser at undgå investeringer i tobaksaktier. Mere end 35 pensionsfonde i Australien, CalPERS - pensionsfond i USA, Fonds de Reserve pour Les Retraites I Frankrig, AP4 I Sverige, Irish Sovereign Wealth Fund og senest det globale forsikringselskab AXA er ophørt med at investere i tobaksaktier.

I Danmark er der også en begyndende trend for at ophøre med investering i tobaksindustri. Det ses bl.a. hos LEGO, Københavns Kommune, Odense Kommune, Lægernes Pensionskasse.

Kræftens Bekæmpelse medvirker aktivt til at skabe personlig kontakt mellem Bronwyn King /Tobacco Free Portfolios og administrerende direktører for danske pensionsfonde.

Om Bronwyn King.

Dr. Kings afsæt er en dyb, personlig undren over, at hun via sin egen pensionsordning så at sige var medejer af den tobaksindustri, der med sine produkter skader og dræber mange af de patienter, hun som onkolog møder i sit arbejde. Bronwyn King er en meget overbevisende, troværdig og dybt engageret ildsjæl, der berører alle hun taler med om sin sag. Det gør stærkt indtryk, når Bronwyn King fortæller om de 6 mio. mennesker, der årligt dør på grund af tobaksrygning, om tobaksindustriens brug af børnearbejde, og metoder til at rekruttere nye rygere i alle aldre verden over mv.

Det der startede som en enkelt kvindes kamp, bliver nu bakket op flere steder fra.

Det gælder blandt andet UICC og Cancer Research UK. Sidstnævnte har således støttet initiativet ved at stille en Dr. Med. til rådighed på halv tid gennem to år. ECL - Association of European Cancer Leagues har inviteret Bronwyn King som gæstetaler på ECL Konference 28. september 2017.

Den nordiske strategiske indsats

Tobacco Free Portfolios har hidtil overvejende været båret af frivillig indsats, egne midler og ad hoc økonomisk støtte. Den øgede indsats og en fortsat succes indebærer behov for et vist stabilt økonomisk grundlag.

Kræftens Bekæmpelse foreslår, at NCU som et strategisk initiativ aktivt støtter Bronwyn Kings initiativ og arbejde i Tobacco free Portfolios.

Dette kan gøres ved

- at medvirke til facilitere personlige kontakter til pensionsselskaber i de enkelte nordiske lande,
- at yde økonomisk støtte til omkostninger til nødvendig rejse- opholds og mødeaktivitet med et 3 årigt sponsorat på 20.000 US \$ årligt fra NCUs strategiske pulje (ca. 140 – 150.000 d.kr. årligt)

Bilag (5): (Tobacco Free Portfolios Tool Kit.

Bilag (6) *Tobacco Free Portfolios Giving Circle.*

Indstilling

Kræftens Bekæmpelse indstiller, at NCU drøfter forslaget og træffer beslutning om gennem NCUs strategiske midler at støtte *Tobacco Free Portfolios* ved at tegne et 3-årigt "Gold"sponsorat på 20.000 US \$ årligt fra NCUs strategiske pulje svarende til en årlig udgift på 140 – 150.000 DKK.

8. "A dreamer's World".

Bilaga (nr. 7)

Collaboration, skrivelse daterad den 16 maj 2017.

Kommentarer

Detta är en ansökan från Jean-Claude Boeke om finansiellt stöd till en kortfilm om medvetande om cancer och den effekt som tumör har på hjärnan. Denna film kommer att visas på många filmfestivaler, såsom Cannes och Berlin. Inget belopp är specificerad i nämnda ansökan.

Förslag

Att styrelsen tar ställning till föreliggande ansökan.

Information och diskussion

9. Kræftens Bekæmpelses Omdømmesstrategi og etiske retningslinjer.

Bilagor (nr. 8, och 9)

- Kræftens Bekæmpelses omdømmestrategi.
- Kræftens Bekæmpelses etiske retningslinjer.

Kommentarer

Kræftens Bekæmpelses kommunikationschef Katrine Asp-Poulsen præsenterer Omdømmestrategi og Etiske Retningslinjer og redegør for baggrund, formål, visioner og implementering.

Förslag

Derefter følger spørgsmål og debat.

10. Tillgänglighet till nya cancermediciner.

Bilaga (nr. 10)

Kortlægning af lægemiddelområdet i de nordiske lande. Danmark, Finland, Grønland, Island, Norge och Sverige. KORA Det Nationale Institut for Kommuner og Regioners Analyse og Forskning. København, November 2016.

Kommentarer

De mediciner som traditionellt används för att bekämpa cancer har kraftiga biverkningar eftersom de slår mot både cancerceller och kroppens vanliga celler. Nu har det tagits fram nya mediciner som enbart attackerar cancercellerna och man menar att metoden slår mot alla cancerformer. De nya medicinerna är mycket effektiva men dyra och i många europeiska länder tror man att dessa kommer på sikt att spräcka sjukvårdsbudgeten. Nordiska ministerrådet har de senare åren diskuterat förutsättningarna för tätare samarbete på läkemedelsområdet. En ny rapport "Kortlægning af lægemiddelområdet i de nordiske lande" anses kunna underlätta samarbete mellan länderna vad gäller både tillgång till mediciner och åtgärder att hålla priserna ner.

Förslag

Anser ni att NCU skall arbeta för att säkra att nya cancermediciner skall bli tillgängliga i de nordiska länderna? Om svaret är ja, hur kan tillgängligheten bli säkrad i respektive land?

11. Evaluering av NCU:s forskningsinitiativ.

Bilaga (11)

E-mails från Hans Storm och Ole Alexander, daterade den 13 mars 2017.

Kommentarer

Frågan diskuterades på styrelsemötena den 25 november 2016 och den 17 februari 2017. Ole Alexander, Hanns Storm och Þórunn Rafnar fick i uppdrag att assistera sekretariatet i att bereda saken för ytterligare behandling. Det har varit brevväxling mellan medlemmarna i arbetsgruppen, men enligt uppgift kommer man inte att vara beredd med något upplägg inför mötet i Köpenhamn den 29 maj. Ordförandeskapslandet menar dock att de idéer som redan väckts bör diskuteras vid för att kunna säkra att man kommer vidare med saken. Dessa gäller både systematiskt litteratursök och användandet av särskilt frågeschema.

Förslag

Att styrelsen informeras om hur arbetet fortskrider.

12. Cancerresolutionen. (A70/32).

Bilaga (nr. 12)

Cancer prevention and control in the context of integrated approach. (A70/32).

Kommentarer

Resolutionsförslag beträffande cancerprevention och kontroll kommer att tas upp under Världshälsoförsamlingens församling i Geneva den 22- 31 maj. Svenska delegationen, som har följt frågan sedan styrelsemötet i Stockholm den 17 februari, kommer att informera om sakens beredning inför Världshälsoförsamlingen möte.

Förslag

Att styrelsen tar informationen för kännedom.

13. Årsrapporterna och hemsidan.

Det har framkommit synpunkter på vad de årliga rapporterna skulle som regel förmedla. Liksom vilken ambitionsnivå man skall hålla vad gäller rapporternas längd och innehåll? Revidering av NCU:s hemsida är redan i gång och länderna har redan utpekat sina kontaktpersoner.

14. Nationella rapporter.

Delegationerna redogör för situationen i respektive land.

Avslutande frågor

15. Övriga frågor.

- Nordisk arbetsgrupp för arbetsgrupp för kunskapsutbyte och forskning för pakkeförlopp.

16. Kommande möten.

Efter mötet i Köpenhamn den 29 maj planeras styrelsemöten i Stavanger den 29 augusti och i Reykjavík den 17 november.

Länderna informerar om vilka deltar i ANCR SYMPOSIUM 2017 Stavanger den 29-31 augusti. Möte i NCU-styrelse blir den 29 augusti kl.: 15:00 – 17:00 och gemensamt möte med ANCR-styrelse kl.: 17:00 – 18:00. **(Bilaga 12 og 13).**

DELTAGARLISTA

Danmark

Leif Vestergaard Pedersen
Hans Henrik Storm
Elizabeth Hjorth

Finland

Sakari Karjalainen
Carita Åkerblom

Island

Ragnheiður Haraldsdóttir (ordf.)
Ingimar Einarsson

Norge

Kirsten Haugland
Ole Alexander Opdalshei

Sverige

Ulrika Årehed Kågström
Susanna Wärn

Färöarna

Durita Tausen

Bilagor

1. Projects overview.- Agreed by the Board of NCU, in May 2017, All amounts in EURO.
2. NORDSCREEN. E-mails from Hans Storm and Stefan Lönberg, daterad den 18. maj 2017
3. Proposal for specific initiatives in the period 2018 - 2020 on each of the 5 main topics in NCU strategy plan.
4. NCU strategy for the years 2015-2018.
5. Tobacco Free Portfolios Too Kit.
6. Tobacco Free Portfolios Giving Circles.
7. Collaboration, skrivelse daterad den 16. Maj 2017.
8. Kræftens Bekæmpelses Omdømmesstrategi.
9. Kræftens Bekæmpelses etiske retningslinjer.
10. Tillgänglighet till nya cancermediciner.
11. Evaluering av NCU:s forskningsinitiativ.
12. Cancerresolutionen (A70/32).
13. ANCR SYMPOSIUM 2017 i Stavanger 29-31 augusti. Preliminary program.
14. ANCR SYMPOSIUM 2017 i Stavanger 29-31 augusti. Pre-symposium Tuesday 29th of August, 14:00-17:00.

Bilaga 1



Strategic projects overview

Project overview - Agreed by the Board of NCU, in May 2017, All amounts in EURO

		Total support	Planed in 2015	Planed in 2016	Planed in 2017	Planed in 2018	Planed in 2019
Confirmed financial support							
Secretariat for Nordic NECT	1	148.000			98.000	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	16.400	51.900	196.050	131.650	0
Actual payments							
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	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

		Total support	Planed in 2015	Planed in 2016	Planed in 2017	Planed in 2018	Planed in 2019
Unpaid confirmed financial support							
Secretariat for Nordic NECT	1	148.000			98.000	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	0	16.400	114.400	85.500	0

Criteria for strategic projects funded by the NCU

Application letter

Projects description

Budget information incl. other funds

CV and relevant information

From our strategy for funding:

Uniquely suited to be implemented in part at least in the Nordic countries...

Aimed at enhancing infrastructure and cooperation....

Health care professionals or researchers in two or more Nordic countries should be involved and the effect should be synergistic...

Major emphases to enhance collaborative research, research related projects ...

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 NCU.

Bilaga 2

NORDSCREEN

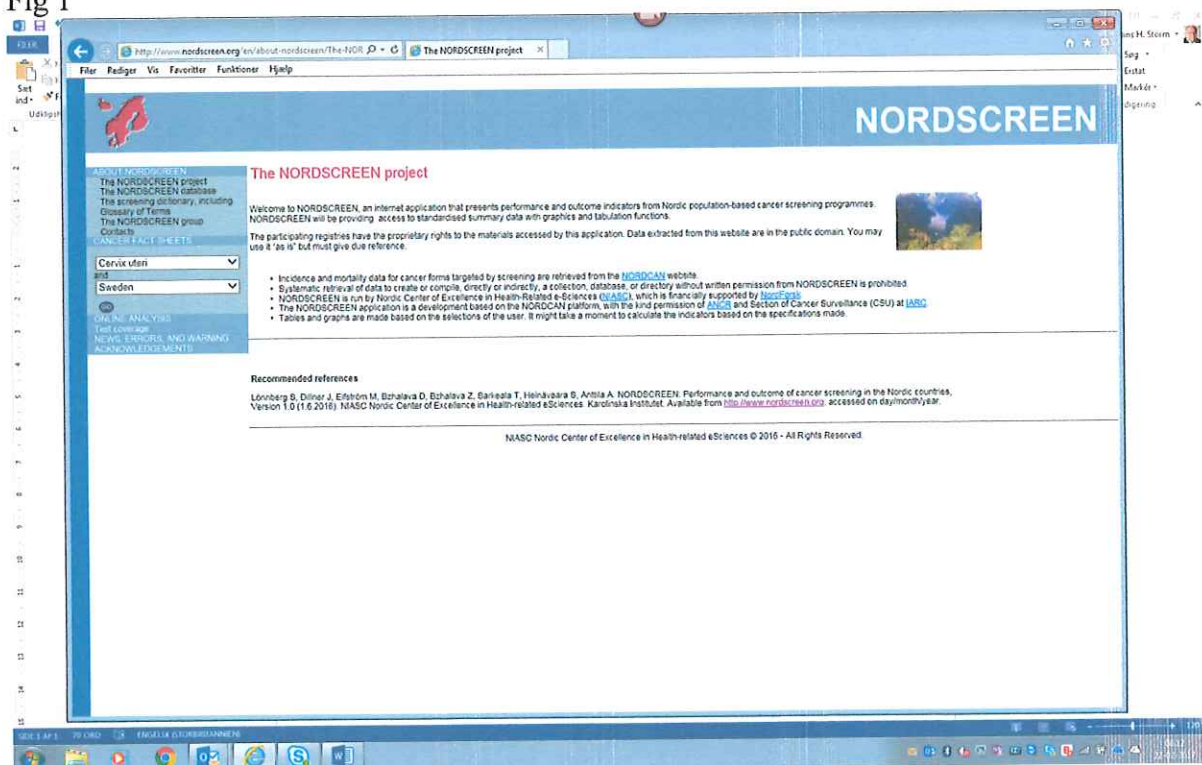
Draft of a response from the board of the NCU to NORDSCREEN by Hans Storm, submitted February 22nd to board members.

Reflections from StEfan Lönberg dated may 18th 2017

NORDSCREEN -- Comments to application by Stefan Lönberg.

The aim is to develop a database with quality indicators for screening programmes and use NORDCAN like software for continuous feedback on programme performance to stakeholders. To this, the NORDSCREEN group received the NORDCAN source code and set up a test site (Fig 1). According to this Nordic Center of Excellence runs the project in Health-related eSciences, Karolinska Institute supported by NordForsk.

Fig 1



In the background part of the project description it is stated “Many European Countries and all Nordic countries have population based mass screening registries with individually identifiable data on participation and outcomes” however claimed “infrequently published” and “not fully exploited”. It is also claimed that “publicly available indicators may improve data collection and monitoring” and “greatly ease the provision of relevant and tailored data to decision makers”.

The main recommendations from the CANCON project WG 9 – screening authored by the applicant are clear (copied below):

1 National structures for governance of screening are here identified as important requirements for evidence-based decision-making and for establishing adequate legal, financial and organizational frameworks for effective cancer screening programmes with integrated quality assurance. We recommend transparent, structured and publicly documented decision making, informed political commitment and broad stakeholder involvement in order to build strong professional support for the aims and means of the screening programme. Governance structures recommended here are currently lacking in many European settings, which may contribute substantially to inequalities in cancer prevention outcomes observed both between and within countries.

HHS Comment: Governance structures exist in the Nordic countries

2 Organization for the practical implementation and the continual gradual improvement of population-based cancer screening programmes further requires careful coordination of this multistep process with feedback and corrective modification at each step, plus revolution of the quality circle. Information systems that permit registration and monitoring of process and outcome are crucial for maintaining current levels of quality, and for guiding further improvement.

HHS Comment: Systems exists in the Nordic countries

3 Evaluations of the benefit-harm balance and cost-effectiveness of screening are required periodically for existing programmes and prospectively for new screening programmes. The population targeted by screening have an ethically mandated right to clear information on benefits and harms for an informed choice about participation. Indicators for equity in participation and health outcomes need to be included in the routine quality assurance capabilities of population-based screening programmes.

HHS Comment: Already ongoing in the Nordic countries

4 New screening programmes require step-wise decision-making which includes the establishment of evidence of effectiveness, benefits that outweigh the harms and cost effectiveness. Once evidence exists to support these criteria, implementation research in each country is needed to assess the feasibility of fulfilling the national requirements in practice. In light of currently available evidence, some prostate cancer screening policies may be cost effective but questions remain on the optimal benefit-harm balance. Forthcoming results of European trials are expected to inform policy-making on lung cancer screening in Europe. New trials need to be financed to investigate optimal strategies for gastric cancer screening.

HHS Comment: Cost effectiveness in general agreed in the Nordic countries but a lot of discussion on the benefit-harm tipping point.

In the KIN (Kreftbildet i Norden) project Matti Hakama, Finish Cancer Registry estimated the potential of the 3 ongoing screening programmes for cancer (Cervix, Breast and Colo-rectal) to be able to reduce the overall cancer mortality by about 5% so screening for cancer is an important measure with short term impact compared to tobacco control and other preventive activities at the population level.

General comment to the application:

According to the internationally and by WHO adopted guidelines for population based screening, such an activity should not be implemented unless both treatment services and monitoring coverage and efficacy of the screening programme is in place. A long list of requirements was developed over 20 years ago by the WHO, and supplemented by M. Hakama in the various volumes of the WHO manual for cancer control. It is obvious a population based screening programme will have many similarities (methods, diagnostic tools, invitation strategies) but also differences dictated by the social and health care environment of a country. This will be clear from the routine analysis of the programmes mandated to take place for a massive public health activity in any country.

National evaluations are ongoing at the responsibility of the providers of screening in each country, so it is debateable if a joint continuous presentation software will have any influence on the screening policy in any country. Rather the already ongoing national evaluation of screening programmes need strengthening.

Benchmarking to other countries and other programmes need not to be available on a daily or even annual basis but is probably better done in specific peer reviewed research projects designed for exactly this purpose and used in the policy lobbying – as was the cancer for the Nordic cancer incidence, mortality and prevalence and survival comparisons.

The key question for the NCU

- If the build up a database and software, i.e. the creation of a Nordic screening registry will have substantial impact on the cancer incidence and mortality or cancer patient care.
- If it will assist the cancer societies in their policy and lobbying for improved earlier diagnose and treatment or be in alignment with the Report to the Nordic council of ministers by Bo Könberg on registry based research.
- With the ongoing debate on screening it is doubtful if this instrument will be of any help, whereas a strengthening of national evaluations on the contrary may have.

Budget:

The budget of 612 310 € must be seen in the context of the NCU capabilities.

Taking the example of NORDCAN (as used by the applicant), this database and software came to life differently. It was built on a series of specific projects since 1995 partly financed by the Nordic council of ministers and later co-financed by the NCU. The software was an added benefit of peer reviewed publications and projects each carefully described and evaluated by granting bodies. Hence it was investigator driven interests by staff already dealing with the data in national organisations.

Given the NORDSCREEN was provided with the NORDCAN source codes and indicators do exists – and the NORDCAN programming was done along other work of a programmer at the IARC, it is hard to believe the NORDSCREEN – with a much simpler data structure - need a full time programmer for 3 years. Further the NORDCAN group (as one may expect the screening employees) provided their services (and still do) as part of their daily work i.e. financed by the national mother institutes. To have a full time scientist for 3 years is not justified, and in general the budget lack justification.

To this adds the principle that the Danish Cancer Society do not pay overhead in grants, and social fees is normally part of the salary (and differs between countries). Further inflation is not at present 3% - it is much less.

HHS conclusion: A major revision of budget, linked to a specific workplan, based on thorough description on existing national evaluations of screening programs in all Nordic countries, an indicator list and foreseen analysis and publications is needed to assess if there will be added value of NORDSCREEN.

Dear Ragnheidur,

Thank you for your consideration of the application of funds for Nordscreen.

I have not amended the current application based on Hans's comments for this occasion but would like to make a few reflections.

I acknowledge that Nordcan was set up differently and that that example could also be followed by applying for funds for a scientific study at a time and letting the website and data collection develop by virtue of a series of scientific projects.

In Nordscreen we explicitly wanted to start with making indicators available in the application in order to showcase the possibilities of the approach and hopefully thereby further motivate national registers to participate (so far without compensation). Scientific publications are also planned but the project is not spearheaded by journal papers, rather the application itself and the perceived usefulness it might provide for stakeholders in cancer screening.

We have noticed that the programming and database management part of the project has consumed more time and resources than we imagined at the beginning. We were not able to use the Nordcan platform efficiently in the end and have now developed the website and application on other publicly available formats. See www.nordscreen.org for the current look.

It seems just about possible at the moment that the project may continue in some form also without additional dedicated resources, in that case relying on the motivation to invest time and resources of register employees in the course of their day-to-day work. However, a worthwhile effort would of course be much easier to secure with funding and here every bit would help. The proposed budget would cover much of the resources required for developing the site, application, and implementing a set of core standardised indicators; a smaller budget would require more contributions in kind from the participants. A project manager would in any case be a necessity together with some resources for programming.

A long term solution would still be needed after initial set-up, to make it a viable, updated and sustainable function. For that, agreements need to be made with the participating registers. Here, lessons from Nordcan could again be valuable, and also provide opportunities for synergies.

Best of regards,
Stefan

Bilaga 3

Proposal for specific initiatives in the period 2018 - 2020 on each of the 5 main topics in NCU strategy plan.

Re: NCU strategy plan Topic 1:

Reduce risk of cancer; implement existing knowledge with the aim of preventing up to 40% of cancer diseases

Proposal for specific focus 2018 – 2020:

Dissemination of the European Code against Cancer in the Nordic countries

The European Code against Cancer is a preventive tool aimed at reducing the cancer burden by informing people how to avoid or reduce carcinogenic exposures, adopt behaviours to reduce the cancer risk, or to participate in organised intervention programmes. The Code should also form a basis to guide national health policies in cancer prevention. The Code is based on extensive, scientific research and gives a clear overview of where to intervene as individuals and society. By taking action we may prevent up to half of all cancer incidences. <http://cancer-code-europe.iarc.fr/index.php/da/>

The European Cancer League works together with the individual countries to communicate the European Code against Cancer to the population and the decision-makers. The populations and the society models of the Nordic countries are similar, and even though there are some differences in health behaviour and cancer risk, to a high degree the same factors are considerable to prevent cancer.

NCU could work out a joint Nordic strategy to disseminate and implement the European Code against Cancer and transform it to relevant information activities in the Nordic countries. Possibly in the form of joint or coordinated initiatives on World Cancer Day, World No Tobacco Day and others, or even better in the form of a joint Cancer Prevention Month after the American pattern with broad information on the European Code against Cancer and the benefits of prevention and at the same time fundraising for the prevention work of the Nordic cancer societies. <http://www.aicr.org/cancer-prevention-month/>

Proposed action:

- the NCU Presidency invites representatives of the NCU members to a working group meeting, to present ideas and identify possibilities.
- the working group submits and present a report on the group's assessments to the NCU board
- where appropriate and after discussion with the board the working group can submit application for project from the strategic pool.

Re: NCU strategy plan Topic 2

Improve life with cancer; optimal diagnosis and treatment according to high international standards including rehabilitation and palliative care as necessary.

Proposal for specific focus 2018 – 2020

Monitoring, preventing and treating late effects among cancer survivors

The survival after cancer treatment is increasing in the Nordic countries and will increase in the coming years. Thus more and more cancer patients are becoming long-term survivors and in the Nordic countries more than 1,2 million inhabitants are currently under cancer treatment or are cancer survivors. Many cancer patients may develop a variety of physical, socio-economic and psychological late effects leading to reduced quality of life and functional capacity. Studies indicate that approx. 50% of cancer patients may develop late effects. In addition cancer survivors often experience diverse, not yet fully described chronic morbidities which may result in increased late mortality from causes other than relapse. The prevention and management of late adverse effects after cancer should be an integrated component of the cancer care. However, knowledge about the prevalence of late-effects in specific diagnostic groups and how late-effects develop over time is scarce as well as evidence in the field of routine clinical management of late effects. Therefore, many cancer survivors experience that the adverse and often serious consequences of the cancer and its treatment are often not adequately addressed. A Nordic collaboration with a focus on late effects after cancer may focus on collecting and comparing Nordic data on the prevalence of late effects related to diagnoses and treatment in order to identify risk groups and possibilities for prevention. Also, evidence in the field of routine clinical management of late effects could be shared and developed at a Nordic level.

Proposed action:

- the NCU Presidency invites representatives of the NCU members to a working group meeting, to present ideas and identify possibilities.
- the working group submits and present a report on the group's assessments to the NCU board
- where appropriate and after discussion with the board the working group can submit application for project from the strategic pool.

Re: NCU strategy plan Topic 3:

Support joint and comparable monitoring of cancer and outcome as a basis for equal and best possible care, and clinical research.

Proposal for specific focus 2018 – 2020:

Nordic collaboration on monitoring the implementation of standardized cancer patient pathways

Cancer patient pathways – organized in standardized packages – with clearly defined working routines and cooperation structures renders it possible to establish patient pathways that without unnecessary delays can provide the individual patient with an unbroken pathway from general practice through hospital care.

In Denmark, 21% of cancer patients registered with a standardized cancer patient pathway for an organ specific type of cancer have a longer than recommended trajectory duration, and 12% of incident cases of cancer are never included in a standardized cancer pathway. So far, little knowledge exists on patient pathways that does not comply with the relevant standardized cancer patient pathways.

The Danish Cancer Society is developing a model for characterizing pathways of lung cancer patients with either longer than recommended trajectories or patients not included in a standardized lung cancer patient pathway. The developed model can be used to analyze pathways for other cancer types, and include patient specific information on eg. Socio-economic position and patient reported outcomes and information from primary health care.

Monitoring the implementation of standardized cancer patient pathways with the above-described model will support the existing monitoring and support continued focus on ensuring the best possible pathway from the suspicion of cancer to actual treatment, and the best possible chance of survival for all cancer patients.

Norway and Sweden have now implemented standardized cancer patient pathways similar to Denmark, and monitoring the implementation of cancer patient pathways in a Nordic collaboration will strengthen the NCUs work for best possible care for cancer patients.

Proposed action:

- the NCU Presidency invites representatives of the NCU members to a working group meeting, to present ideas and identify possibilities.
- the working group submits and present a report on the group's assessments to the NCU board
- where appropriate and after discussion with the board the working group can submit application for project from the strategic pool.

Re: NCU strategy plan Topic 4:

Nordic countries as leaders in excellent collaborative cancer research, both basic and clinical, utilising the special conditions related to well-monitored populations and national biorepositories.

Proposal for specific focus 2018 – 2020:

“Timely identification of cancer patients at high risk for relapse and treatment induced chronic disease”

Too many *cancer patients* do not respond satisfactorily to the first-line treatment, they are offered (1). And, too many *cancer patients* develop severe, or even life-threatening chronic conditions after completed treatment (2-4). Presently, the treating physician cannot foresee or explain why some patients benefits greatly of the treatment offered, while other patients – suffering from an apparently identical cancer – have no use at all of the very same treatment. Similarly, a given cancer treatment may in some patients lead to severe chronic diseases of e.g. the heart, and the respiratory, urinary or endocrine systems, while the same treatment in other patients is without late effects. Today, the treating physician have no reliable markers prior to start of treatment that can guide in the search for the most effective and lenient treatment for the individual cancer patient seeking help.

Thus, there is a need for the invention of tumour biomarkers that can reliably identify cancer patients *at high risk* for being non-responders to the standard treatment, as well as personal biomarkers that can reliably identify cancer patients being *at high risk* for developing severe or life-threatening late effects of a given treatment.

Relevant biomarkers exists – they “just” need to be identified.

Helpful results in this important field of research require access to large populations that are well characterised in regard to type of cancer disease, clinical outcomes in respect to relapse-free survival, and risk for late effects in terms of chronic diseases.

The Nordic countries are in the forefront internationally utilising the special conditions related to well-monitored populations followed in a number of health-related national registers, and biological samples stored in national or local, disease-specific biobanks. Thus, the Nordic countries holds unique possibilities – as individual countries or jointly – through an intelligent exploitation of these resources to establish valid biomarkers for the identification of cancer patients at high risk for being non-responders to standard treatment, as well as patients being at high risk for developing severe chronic disease after standard treatment.

Proposed action:

The NCU Presidency will make proposal for action to be discussed by the NCU Board, when Danish Cancer Society's new research director has acceded position

Re: NCU strategy plan Topic 5 a

Joint up-to-date information on cancer to the public

Proposal for specific focus 2018 – 2020:

The art of navigating the ever-changing media landscape – or how to communicate facts and scientific evidence in the post-factual era

Scientific knowledge and formal authority used to be common and safe 'go to'-places when a factual foundation was needed to qualify debates or opinion making. This has long been a strong position for knowledge-based organisations like the Nordic cancer societies

Now there is need for redefining the role as knowledge institution and influencer in a fast changing media landscape and at the same time adapt to new era in which respect for facts and formal authority is declining. In which 'what I feel' can compete with 'what we know' – and sometimes even win the argument. Where anyone with a compelling story can publish it on social media and gain an audience of like minded supporters. Where influencers and modern storytelling engage and move recipients with new, more visual forms of communication. Where the pace in mainstream media is so fast that the all the different news sources often run the same way and create tidal waves of copy-paste news flows.

These are the challenges the Nordic cancer societies face – and the possibilities we need to embrace. Not by giving up objectivity, professionalism and credibility to please the strong trend towards snackable news items that are easy to digest. On the contrary. It is necessary to be ambitious, go against the tide and show that there is an even stronger need now for objectivity, professionalism and credibility in this widespread sea of information, fake news and alternative facts.

The new media situation has to be adapted by playing with all the possibilities of the new platforms and keeping a strong focus on maintaining objectivity, professionalism and credibility while doing so.

The Nordic cancer societies could share insights and efforts of creating and implementing new strategies including both tools on how to master the new media situation and some more fundamental principles that secures a constant focus on reputation management.

Proposed action:

The NCU Presidency invites representatives of the NCU members to participate in workshop

- to share insights and efforts of creating and implementing new strategies including both tools on how to master the new media situation and some more fundamental principles that secures a constant focus on reputation management
- the working group considers to form a network for ongoing inspiration
- the working group submits a report on the working group meeting to the NCU board

Re: NCU strategy plan Topic 5 b

Common Nordic advocacy to influence public policy in the Nordic countries and globally

Proposal for specific focus 2018 – 2020:

Policy workshop for Nordic colleagues in the NCU: Exchange of experiences and mutual inspiration from policy work in the Nordic cancer societies

Agenda setting policy achievements requires profound preparatory work, tight focus and control of interested parties and processes.

The aim of a workshop could be exchange of experiences and mutual inspiration from policy work in the Nordic cancer societies, including identifying subjects/themes suitable for future policy work in the Nordic countries.

The workshop could include presentation and debate on how already obtained selected significant results have been achieved, facilitated by colleagues responsible for the societies' policy work.

Examples on work processes that have resulted in changes for cancer patients and relatives could be covered at the workshop. Instruments and working methods could be shared among the Nordic colleagues. And exchanging of experiences on the use of social medias in policy work could be included.

Each of the member countries should prepare presentations on one or two cases relevant to the other Nordic countries. Problems, dilemmas and priorities in preparation for implementation of the aims should be presented and discussed with the workshop participants.

Ideas and suggestions on subjects/themes suitable for future policy work – nationally as well as on a Nordic level – could be shared and discussed.

Proposed action:

The NCU Presidency invites representatives of the NCU members to participate in workshop

- to share ideas and suggestions on subjects/themes suitable for future policy work – nationally as well as on a Nordic level
- the working group considers to form a network for ongoing inspiration
- the working group submits a report on the working group meeting to the NCU board

NCU strategy for the years 2015-2018

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

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

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

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

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

The main points of the 2015-18 strategy are:

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

Bilaga 5

Se NCU:s Extranet.

Tobacco Free Portfolios. The toolkit. February 2017.



Bilaga 6

Se NCU:s Extranet.

Tobacco Free Portfolios Giving Circle.

Tobacco Free Portfolios Giving Circle



We aim to inform, prioritise and advance tobacco free investment by eliminating tobacco from investment portfolios across the globe.

Bilaga 7

Collaboration, skrivelse daterad den 16 maj 2017.

From: Krabb
Sent: 16 May 2017 12:57
To: Ragnheidur Haraldsdóttir.
Subject: FW: Collaboration
[Fyrirvari/Disclaimer](#)
From: Jean-Claude Boeke [<mailto:info@kaminocinema.com>]
Sent: 16. maí 2017 11:59
To: Krabb
Subject: Collaboration

Hello Nordic Cancer Union

My name is Jean-Claude Boeke and I'm producing the short movie "A Dreamer's World".

I wrote the script in order to bring more awareness towards cancer and the effect a brain tumor has towards the brain so more bolder measures will be taken towards funding brain cancer treatment. That is also why I am writing to you knowing that your institution has a mutual goal in bringing more awareness in a subject that gets easily forgotten.

My twin brother Jean-Paul died from a brain tumor at the early age of 22. Cancer has been a repetitive subject in our lives since the age of 8 until 2010 when his fight ended.

Me and my team have been working on the movie for over 5 years and we have recently finished shooting a few scenes from the movie which was a 2 day production in the beginning of March 2017. Panasonic Sweden has agreed to a collaboration in exchange for photo stills from the movie for marketing values and in return the movie gets endorsed with camera equipment. The movie will be in English in order to reach an international audience, once "A Dreamer's World" reaches its final edit it will be shown in numerous festivals such as Cannes, Sundance, Berlinale and many more.

In order for the movie to reach its completion it is in need of financial production endorsement, the movie has 6 more production days left as well as post production.

Are you and your institution interested in commencing a collaboration with us through endorsing A Dreamer's World financially in order to bring more awareness towards cancer and brain tumor? With this email you will be able to find the movies document in the form of a pdf file and the official website.

Official website: www.drommarnasvarld.com

We are looking forward to hearing more from you.

Kind regards

Jean-Claude Boeke Producer
Ningenno Cinema
Sweden
+46 076 213 35 84
info@kaminocinema.com

Bilaga 8

Se NCU:s Extranet.

Kræftens Bekæmpelses Omdømmesstrategi.

KRÆFTENS BEKÆMPELSE

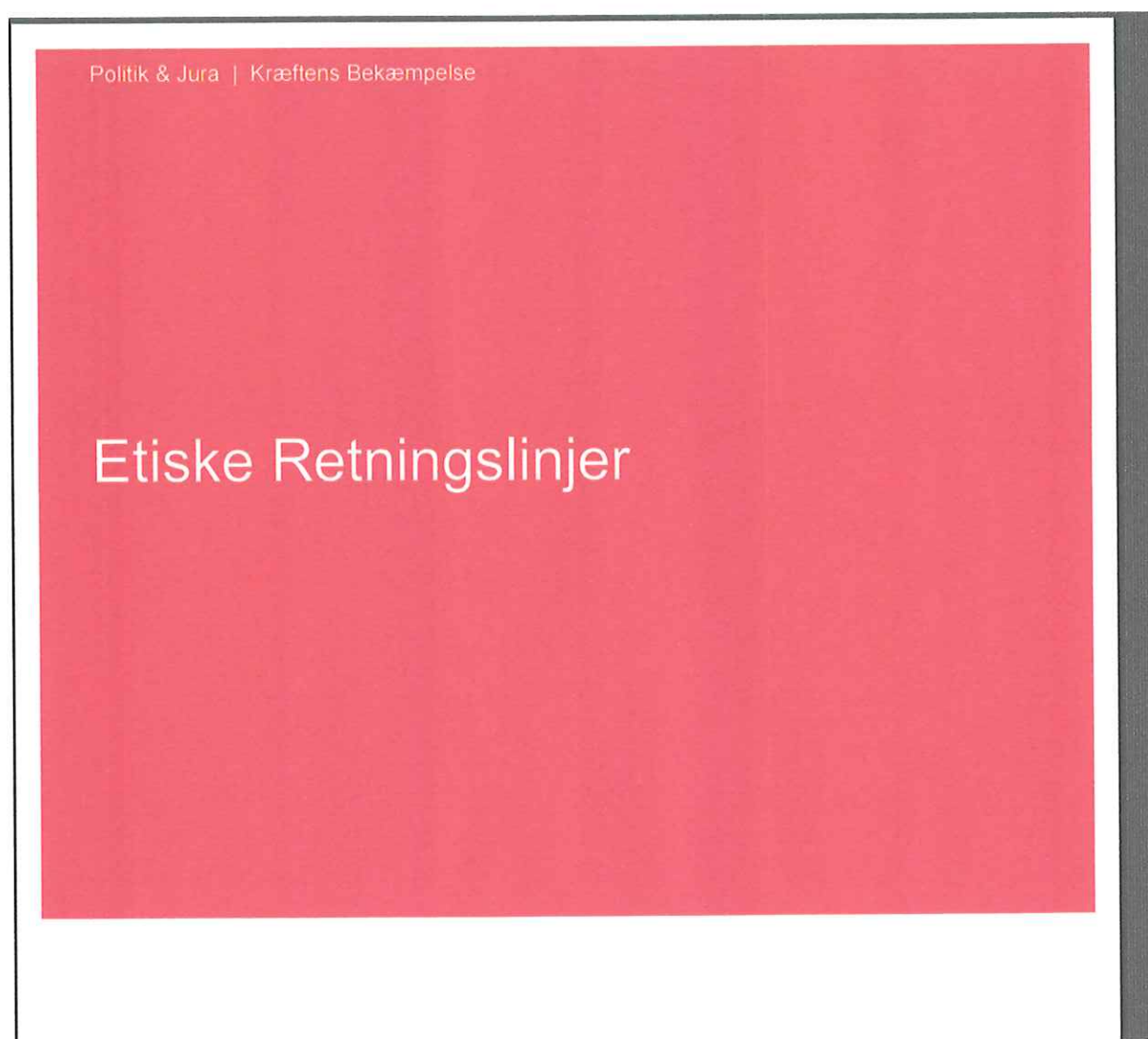
OMDØMMESTRATEGI



Bilaga 9

Se NCU:s Extranet.

Kræftens Bekæmpelses etiske retningslinjer.



Bilaga 10

Se NCU:s Extranet

Tillgänglighet till nya cancermediciner.



Betina Højgaard, Sarah Wadmann, Susanne Reindahl Rasmussen
og Jakob Kjellberg

Kortlægning af lægemiddelområdet i de nordiske lande

Danmark, Finland, Grønland, Island, Norge og Sverige



Det Nationale Institut
for Kommuner og Regioners
Analyse og Forskning

Bilaga 11

Evaluering av NCU:s forskningsinitiativ.

Underlag inte inkommit före utskick.

Bilaga 12

Cancer prevention and control in the context of an integrated approach. A70/32.

http://apps.who.int/gb/ebwha/pdf_files/WHA70/A70_32-en.pdf



World Health
Organization

SEVENTIETH WORLD HEALTH ASSEMBLY
Provisional agenda item 15.6

A70/32
13 April 2017

Cancer prevention and control in the context of an integrated approach

Report by the Secretariat

1. In January 2017, the Executive Board, at its 140th session, considered an earlier version of this report that contained a draft resolution.¹ During the discussions,² an informal drafting group was set up so that consensus could be reached on the text of the draft resolution. Despite progress made by the drafting group, consensus was not achieved before closure of the Board's session and certain paragraphs of the draft resolution remained pending. The Board then agreed that the discussion of those outstanding paragraphs would be continued during the intersessional period.

BURDEN AND TRENDS

2. Cancer is a growing public health concern. In 2012, there were 14.1 million new cases and 8.2 million cancer-related deaths worldwide. The number of new cases is projected to increase to 21.6 million annually by 2030. The greatest impact is in low- and middle-income countries, many of which are ill-equipped to cope with the escalating burden of disease, and where 65% of cancer deaths occur.

Bilaga 13

ANCR SYMPOSIUM 2017 i Stavanger 29 – 31 augusti.



ANCR & NCU SYMPOSIUM 2017

Stavanger, Norway

29. – 31. August 2017

Preliminary program

Tuesday 29. August

- 12:00–17:00 ANCR board meeting
- 13:30–14:00 Registration and refreshments
- 14:00–17:00 Pre-symposium workshop I: Current challenges in coding and registration of cancer
- 14:00–17:00 Pre-symposium workshop II: Missing data and the estimation of cancer survival
- 18:00 Barbeque party on the beach, with games and evening swim

Wednesday 30. August

- 07:00–09:00 Breakfast and morning exercise: morning swim or jogging
- 09:00–09:10 Opening
- 09:15–16:00 Plenum and poster sessions
- 18:00 Conference dinner with guided tour

Thursday 31. August

- 07:00–09:00 Breakfast and morning exercise: morning swim or jogging
- 09:00–12:30 Plenum session
- 12:30 Farewell lunch

Registration and payment

The conference fee is 3 300 NOK and includes meals and conference dinner. The conference fee should be paid to the CRN via this link for registration: http://www.deltager.no/ANCR_2017

Accommodation

The symposium will take place at the Sola Strand hotel, which is easily accessible by bus or taxi from Sola airport. For booking, please contact the hotel directly: booking@sola-strandhotel.no
Conference price: single room 1100 NOK per night, double room 1300 NOK per night. **NOTE:**

Mention "ANCR 2017" to receive the conference price.

Deadlines

Abstract submission deadline: 10 May 2017

Registration deadline: 25 June 2017

Contact information: e-mail: ancr2017@kreftregisteret.no, phone: +47 22 92 88 03

Bilaga 14



ANCR & NCU SYMPOSIUM 2017

Stavanger, Norway
29. – 31. August 2017

Pre-symposium

Tuesday 29. August, 14:00-17:00

Pre-symposium workshop I: Current challenges in coding and registration of cancer

Who should attend: coding staff and others with interest in cancer coding and registration. The main aim is to discuss some of the current challenges in the cancer registration.

Points of discussion are:

- Differences across borders regarding coding histology reports
- Death certificates
- Classifications in coding
 - which systems are in use today (ICD-O-2, ICD-O-3, WHO)
 - how often should they be updated
- Challenging cases
 - Multiple primaries in different topographical sites
 - Contributions presented in advance are welcome

(Mail to: torhild.lane@kreftregisteret.no)

Pre-symposium workshop II: Missing data and the estimation of cancer survival

Who should attend: epidemiologists, statisticians, and PhD-students.

Ass. Professor of Epidemiology Ula Nur from Department of Public Health, Qatar University, will introduce the topic, and the talk is followed by a practical session. The participants need to bring their own laptop, and Stata will be the primary software.

Contact information: e-mail: ancr2017@kreftregisteret.no, phone: +47 22 92 88 03

