

Finnish Cancer Society/Finnish Cancer Registry

NORDSCREEN

Helsinki, 7 February 2017

Stefan Lönnberg

Nordic Cancer Union Strategic Funds for Improvement Projects - Application letter

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

Aim

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

Background

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

Alignment with NCU strategy

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

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NORDSCREEN – Budget information

Helsinki, 7 February 2017
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Project: Interactive joint NORDic database on performance and outcome indicators of cervical cancer SCREENing (NORDSCREEN)

Project resource requirements in person months:

Year	Secured funding	Funding needed						
	Coordinator/scientist in Finland	Complementary funding needed for coordinator/scientist	Programmer / IT-developer	Sweden	Norway	Iceland	Denmark	Stakeholder meetings
2017	6 months (m)	4 m	10 m	2 m	2 m	2 m	2 m	2 meetings
2018	6 m	6 m	12 m	2 m	2 m	2 m	2 m	2 meetings
2019	-	12 m	12 m	2 m	2 m	2 m	2 m	2 meetings

Funding need in euros:

Euro

Salary	2017	2018	2019
Coordinator/Scientist Finland	18,000	27,810	57,289
Programmer/IT-developer	45,000	55,620	57,289
Sweden	9,000	9,270	9,548
Norway	9,000	9,270	9,548
Iceland	9,000	9,270	9,548
Denmark	9,000	9,270	9,548
Social fees & employer payments (28% of above)	28,285	34,308	43,341
Stakeholder meetings	6,000	6,000	6,000
Travel/Conference	3,000	3,000	3,000
Overhead (20% of above)	27,257	32,764	41,022
Sum of year	165,559	198,599	248,151
SUM TOTAL 2017-2019			612,310

A 3% annual salary increase is included; base-salary (2017) in calculation is 4,500€ across the board.

Curriculum Vitae, Joakim Dillner

Department of Laboratory Medicine, Karolinska Institutet, 141 83 Stockholm, Sweden;
e-mail: joakim.dillner@ki.se

University degree

1995: M.D. (Doctor of Medicine), Karolinska Institutet, Stockholm, Sweden.

Doctoral degree

1986: Dr. Med. Sc. in Tumor Biology, Karolinska Institutet, Stockholm, Sweden.
Supervisor: Professor George Klein.

Relevant post-doctoral experience

1988-1992: Research Assistant, Dept of Virology, Karolinska Institutet, Stockholm, Sweden. Four-year position awarded by the Swedish Medical Research Council.

1986-1988: Postdoctoral Research Fellow at the Dept of Molecular Biology, Research Institute of Scripps Clinic, La Jolla, California, USA.

Associate professorship "Docent"

1990: Docent in Virology, Karolinska Institutet, Stockholm, Sweden.

Present employment, time of appointment

2009-present: Professor in Infectious Disease Epidemiology. Karolinska Institutet, Stockholm, Sweden.

2012-present: Director of the Swedish National Quality Registry for Cervical Cancer Prevention (www.NKCx.se).

2014-present: Head of Unit, Cervical Cancer Prevention Center, Karolinska University Hospital Laboratory, Dept. of Clinical Pathology & Cytology. The Unit performs all HPV tests in the cervical screening program, biobanking of cervical samples and is also responsible for the NKCCx.

2017-present: Head of Research at the Karolinska University Laboratory.

Previous employments and time of appointments

2002-2007: National Coordinator for the Swedish National Biobanking Program, a 54 million SEK program within the Wallenberg Foundation Consortiums in Functional Genomics (SWEGENE and Wallenberg Consortium North). 50% of time appointment, on leave of absence from professorship.

2001-2004: Project leader the Swedish Institute for Infectious Disease Control Biobank.

2011-2012: Senior Visiting Scientist, WHO/IARC (International Agency for Research on Cancer).

2001-2010: Professor of Virology, particularly Molecular Epidemiology. Dept. of Medical Microbiology, Lund University, Malmö, Sweden.

2001-2012: Clinical appointment in the Department of Clinical Microbiology, Region Skåne, devoted to managing the regional biobank in clinical microbiology, the regional cervical screening registry and the WHO Global HPV Reference Laboratory

1998-2003: Six-year position as Senior Researcher in the subject area "Molecular Epidemiology", awarded by the Medical Research Council of Sweden.

1996-1999: Visiting Professor, Dept of Infectious Disease Epidemiology, Finnish National Public Health Institute, Helsinki, Finland, with teaching responsibility at the

- Postgraduate School of Epidemiology, Tampere University School of Public Health, Tampere, Finland. Visiting professorship funded by the Nordic Academy for Advanced Studies.
- 1993-1997: Six-year position as Cancer Researcher, awarded by the Swedish Cancer Society, at the Microbiology and Tumor Biology Center, Karolinska Institutet.
- 1990-2000: Associate professor in Virology at the Karolinska Institute.
- 1988-1992: Research Assistant at the Dept of Virology, Karolinska Institutet. Four-year position awarded by the Swedish Medical Research Council.
- 1986-1988: Postdoctoral Research Fellow at the Dept of Molecular Biology, Research Institute of Scripps Clinic, La Jolla, California, USA.

Commissions of Trust

- 2011 - present: Member of the Board of the Biobanking Programme of the Research Council of Norway
- 2012 - present: Member of the Scientific and Ethical Advisory Board, BBMRI-LPC (Large Prospective Cohorts). EU FP7 project on infrastructure for medical research (www.bbmri-lpc.org)
- 2013 - present: Chairman of the Board, the WHO/IARC Low & Middle Income Countries Biobank & Cohort building Network (BCNet) (www.iarc.fr/bcnet)
- 2009 – 2015: Member of the Board of Research of the Swedish Cancer Society.
- 2002 – 2007: Member of the prioritisation committee for Epidemiology of the Swedish Cancer Society. 2006 also Acting Chairman of the committee.
- 2001 - 2005, 2007: Member of the prioritisation committee for Microbiology of the Swedish Research Council.
- 2004 – 2008 Member of the Board of the Norwegian Functional Genomics initiative FUGE (www.fuge.no), appointed by the Research Council of Norway.
- 2002 – 2005: Member of the Steering Group of the Norwegian National Cervical Cancer Screening Program, appointed by the Norwegian Ministry of Health.
- 2003 – 2007: Member of the prioritisation committee for Clinical Research, Skåne Region, Sweden.
- 1999-2006: Expert evaluator, 1st 2nd and 3rd call of the Biomed 5, Infectious Diseases, and Biomed 6, Cancer area and Infectious Diseases, European Union Biomedicine and Health programme, Brussels.
- 1997: Member, the Roll of Honour of the International Union against Cancer (UICC).

Editor: PLoS One (2014-). Editorial board member: Papillomavirus Research (2015-), Scientific Reports (2015-), International Journal of Cancer (2008-), Clinical & Experimental Immunology (2006-), Journal of Clinical Virology (2009-), Sexually Transmitted Infections (2001-2008).

Scientific Production

433 Medline-indexed publications in the areas of cancer screening, vaccination, tumor virology, epidemiology and research infrastructures. The H-index is 67 with >19000 citations.

Curriculum Vitae 7.2.2017

Name	Stefan Viking Lönnberg
Affiliations	Cancer Registry of Norway; Finnish Cancer Registry (FCR)
Current positions	Researcher– Norwegian Cervical Cancer Screening Programme; screening consultant – Mass Screening Registry at FCR
Diplomas	MD, Dr of clinical epidemiology, BSc in biochemistry
Phone	+358 50 3544910
Email	stefan.lonnberg@cancer.fi
Job address	Unioninkatu 22, 00130 Helsinki

Education

2009-2011	Doctoral studies in clinical epidemiology at University of Helsinki, Finland (PhD)
2001-2006	Medicine at University of Helsinki, Finland (MD)
1999-2000	Biochemistry at University of Oviedo, Spain
1998	Biochemistry and Biotechnology at University of Turku, Finland (BSc)
1997	Army Service and Reserve Officer School, Tammisaari and Hamina, Finland
1995-1996	Biochemistry and Biotechnology at University of Turku, Finland
1993-1995	International Baccalaureate at Li Po Chun United World College of Hong Kong

Professional experience

2016-	Cancer screening consultant, Finnish Cancer Registry
2015-	Researcher, cervical cancer screening programme, Cancer Registry of Norway
2012-2015	Head of section, cervical cancer screening programme, Cancer Registry of Norway
2009-2012	Researcher, Finnish Cancer Registry, Helsinki Field of study: comprehensive evaluation of the cervical cancer screening programme Other tasks: registration and quality control of records and registration processes, European level screening development assignments
2006-2009	General practitioner, Cities of Espoo and Hanko
2006	Ward physician, City of Helsinki, 2006
2000-2001	Researcher at University of Turku Field of study: development of novel methods for <i>in vitro</i> diagnostics

Other merits and experiences

- Project manager (2016-) for NORDSCREEN - development of platform and content for open source access to standardised performance and outcome indicators of cancer screening.
- Partner (2014-) and Cervical cancer screening work group leader in CANCON – European Guide on Quality Improvement in Comprehensive Cancer Control (www.cancercontrol.eu)
- Member of the expert advisory group on HPV primary screening in Norway (2014-2015)
- Head (2014-2015) of the multidisciplinary working group preparing HPV primary screening implementation in the national screening programme in Norway.
- Hjelt Excellence Junior Award 2013.

- Member (2012-2015) of expert group for evidence evaluation of HPV tests in cervical cancer screening in Norway mandated by the Health Directorate
- Member (2012-2013) of “HPV-test for primary screening group 2” mandated by the Health Directorate to develop a proposal for a possible shift to HPV-based screening in Norway.
- Doctoral dissertation: Case-control studies for the evaluation of performance and outcome of organised cervical cancer screening. University of Helsinki 2012.
- Member of faculty in the European Schools of Screening Management (ESSM), 2012-2013, organised within the European Partnership Against Cancer (EPAAC) project at IARC, Lyon.
- Rapporteur and core group member of the cancer screening arm (WP5) of the European Union Seventh Framework Programme contract EUROCOURSE - EUROpe against Cancer: Optimisation of the Use of Registries for Scientific Excellence in research, 2009-2012 (see: <http://www.iarc.fr/en/research-groups/QAS/current-topics.php>). The Work Package deliverables included reports and recommendations on registration, coding and quality assurance of screening programmes, and prioritised projects for the development of cancer screening programmes in Europe.

List of publications in peer-reviewed journals in the last five years as of 7 Feb 2017

- Leinonen MK, Campbell S, Klungsoyr O, **Lönnberg S**, Hansen BT, Nygård M. Personal and provider level factors influence participation to cervical cancer screening: A retrospective register-based study of 1.3 million women in Norway. *Prev Med* 2017 Jan; 94: 31-39.
- Engesæter B, van Diermen Hilde B, Hansen M, Moltu P, Staby KM, Borchgrevink-Persen S, Vintermyr OK, **Lönnberg S**, Nygård M, Janssen EA, Castle PE, Christiansen IK. Quality assurance of human papillomavirus (HPV) testing in the implementation of HPV primary screening in Norway: an inter-laboratory reproducibility study. *BMC Infect Dis* 2016 Nov; 16: 698.
- **Lönnberg S**, Andreassen T, Engesæter B, Lilleng B, Kleven C, Skare A, Johansson K, Fredheim CS, Tropé A. Impact of scheduled appointments on cervical screening participation in Norway: a randomised intervention. *BMJ Open*. 2016;6:e013728.
- Bjørge T, Skare GB, Bjørge L, Tropé A, **Lönnberg S**. Adverse Pregnancy Outcomes After Treatment for Cervical Intraepithelial Neoplasia. *Obstet Gynecol*. 2016 Dec; 128(6): 1265-1273.
- Enerly E, Bonde J, Schee K, Pedersen H, **Lönnberg S**, Nygård M. Self-sampling for Human Papillomavirus Testing among Non-Attendees Increases Attendance to the Norwegian Cervical Cancer Screening Programme. *PLoS One* 2016; 11(4):e0151978.
- Pedersen K, Sorbye SW, Burger EA, **Lönnberg S**, Kristiansen IS. Using decision-analytic modeling to isolate interventions that are feasible, efficient and optimal: an application from the Norwegian cervical cancer screening programme. *Value Health* 2015 Dec; 18(8):1088-97.
- **Lönnberg S**, Hansen BT, Haldorsen T, Campbell S, Schee K, Nygård M. Cervical cancer prevented by screening: long-term incidence trends by morphology in Norway. *Int J Cancer* 2015 Oct; 137(7):1758-64.
- Anttila A, **Lönnberg S**, Ponti A, Suonio E, Villain P, Coebergh JW, von Karsa L. Towards better implementation of cancer screening in Europe through improved monitoring and evaluation and greater engagement of cancer registries. *Eur J Cancer* 2015 Jan; 51(2):241-51.
- Vaccarella S, Franceschi S, Engholm G, **Lönnberg S**, Khan S, Bray F. 50 years of screening in the Nordic countries: quantifying the effects on cervical cancer incidence. *Br J Cancer*. 2014 Aug 26;111(5):965-9.
- **Lönnberg S**, Nieminen P, Luostarinen T, Anttila A. Mortality audit of the Finnish cervical cancer screening programme. *Int J Cancer* 2013 May 1; 132(9):2134-40.
- Leinonen MK, Nieminen P, **Lönnberg S**, Malila N, Hakama M, Pokhrel A, Laurila P, Tarkkanen J, Anttila A. Detection rates of precancerous and cancerous cervical lesions within one screening round of primary human papillomavirus DNA testing: prospective randomised trial in Finland. *BMJ*. 2012 Nov 29;345:e7789. doi: 10.1136/bmj.e7789.
- **Lönnberg S**, Ahti Anttila, Luostarinen T, Nieminen P. Age-specific effectiveness of the Finnish cervical cancer screening programme. *Cancer Epidemiol Biomarkers Prev* 2012; 21:1354-61.
- **Lönnberg S**, Nieminen P, Kotaniemi-Talonen L, Kujari H, Melkko H, Granroth G, Vornanen M, Pietiläinen T, Arola J, Tarkkanen J, Luostarinen T, Anttila A. Large performance variation does not affect outcome in the Finnish cervical cancer screening programme. *Cytopathol* 2012; 23:172-80.
- **Lönnberg S**, Leinonen M, Malila N, Anttila A. Validation of histological diagnoses in a national cervical screening register. *Acta Oncol* 2012; 51:37-44.

[Firmanavn]

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

Background

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

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

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

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

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

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

memo

Decision by the NCU Board

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

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

memo

[Firmanavn]

Til: NCU Board – Meeting in Stockholm 16.02.17
Fra: The Norwegian Cancer Society
Kopi:
Dato: 8. februar 2017
Re: Meeting with NordForsk

Background

In different setting related to Nordic research we in the Norwegian Cancer Society has established contact with different organizations/institution. Through the work in The Nordic Trial Alliance we have worked together with representatives from NordForsk.

NordForsk is an organisation under the Nordic Council of Ministers that provides funding for and facilitates Nordic cooperation on research and research infrastructure.

NordForsk was established in 2005 by the Nordic Council of Ministers for the purpose of strengthening Nordic research. NordForsk's key stakeholders comprise the national research councils, universities and other research-funding bodies. Through the financing and administration of research programmes NordForsk aims to bring together national research groups and promotes research activities of the highest quality.

The purpose of the meeting is both to establish knowledge between our two organizations, and to discuss if there might be possibility for collaboration. Since we both are founders of Nordic research there might be some synergies that could be created.

We know that NordForsk has shown interest in locating partners for common research grants program, and the purpose of the meeting would be to see if this is of interest for NCU – and NordForsk.

Decision by the Board

Will be taken after the meeting.

Ny cancerresolution för beslut på World Health Assembly

Bakgrund

På World Cancer Leader Summit i Paris hösten 2016 la UICCs CEO Cary Adams fram ett förslag om en cancerresolution. *"It is critical to respond ... by uniting as a cancer community to call for a comprehensive and robust World Health Assembly (WHA) cancer resolution in 2017 that would articulate a clear health systems response for cancer and reduce millions of cancer deaths worldwide."* Etienne Krug, World Health Organization, stöttade förslaget och påtalade vikten av att UICCs partners stödjer och påverkar sina politiska beslutsfattare att ställa sig bakom resolutionen på World Health Assembly i maj 2017.

Process

⊗ = genomfört ○ = to do

- ⊗ Letter of interest skickas till the Executive Board (EB) Chair by Member States
- ⊗ Granskning av EB Chair och läggs till EB Agenda
- ⊗ WHO uppdrar åt EB att ta fram en bakgrundsrapport och ett zero draft
- ⊗ Zero draft av resolutionen tas fram för granskning innan EBs möte
- ⊗ Sverige som har en plats i EBs styrelse sammankallade den 11 januari de nordiska länderna till ett förberedande möte inför EBs möte. De nordiska representanterna fann inget i resolutionen som de inte var beredda att stödja. Sverige, som kommer att hålla ett anförande på WHA, kommer på förhand att skicka ut presentationen till de nordiska länderna. Island har meddelat att de högst troligt kommer att ställa bakom.
- ⊗ EB diskuterar Zero draft resolution (klicka för länk) på sitt möte i januari-17 – möjlighet för NGOs att yttra sig.
Medlemsstaterna överens om det mesta, dock några områden med meningsskiljaktigheter, framför allt tillgång till cancerläkemedel. Ett så kallat White paper skrivs fram.
- WHO tillsätter en drafting group som hanterar eventuella justeringar och tar fram en slutversion.
- Resolution presenteras på World Health Assembly (WHA) 17 maj för prövning/godkännande

Zero draft resolution

UICC är övergripande nöjd med skrivningarna i resolutionen men skulle gärna vilja se

- Starkare koppling mellan mödra-, barnavård samt HIV- och primärvård
- Kraftfullare skrivningar om vikten av tillgång till diagnostik, medicinsk behandling och god omvårdnad
- Större fokus på utveckling av finansieringsalternativ för att stärka resurser
- Större fokus i behov av partnerskap mellan flera sektorer (ideell, offentlig och kommersiell) för att nå de cancerrelaterade NCD-målen i Global Action Plan och WHO's hållbarhetsmål.
- World Cancer Day erkänns som en officiell WHO-dag liknande World AIDS Day och World No Tobacco Day.

Cancerfondens hållning

Cancerfonden står bakom resolutionen och kommer att följa förhandlingarna nära. Även om den har störst betydelse för länder i låg- och medelinkomstländer är det angeläget att vårt lands position inte förändras.

För att Sverige ska rösta *för* resolutionen verkar Cancerfonden bland annat genom

- Kontakt med Sveriges hälsoråd, FN-sekretariatet i Genève
- Kontakt med tjänstemän och sakkunniga på departementet.
- Arbeta för att sjukvårdsminister Gabriel Wikström lyfter vikten av resolutionen i sitt anförande på WHA.

Hittills inga invändningar från svenska beslutsfattare.

Förslag till utgångspunkt för samtal på NCUs styrelsemöte 17 februari

- Kommer en resolution att föra cancerfrågan framåt eller ”säkrar” den redan identifierade strategiska områden och pågående arbete?
- Vad kommer att krävas för våra respektive länder för att implementera resolutionen?
- Saknas något viktigt område?
- Hur långt har vi kommit i respektive land, gällande kontakter med regeringen?
- Bör/kan vi göra något tillsammans på nordisk nivå för att säkerställa beslut och innehåll i resolutionen?

Cancer prevention and control in the context of an integrated approach

Report by the Secretariat

BURDEN AND TRENDS

1. 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.
2. In 2012, there were 4.3 million premature deaths from cancer worldwide, 75% of which were in low- and middle-income countries. In order to achieve Sustainable Development Goal 3 (Ensure healthy lives and promote well-being for all at all ages) and its target 3.4 to reduce, by 2030, premature mortality from noncommunicable diseases, including cancer, by one third, an urgent scale-up of actions is needed. This scale-up should include actions that apply also to other targets, such as target 3.a to strengthen the implementation of the WHO Framework Convention on Tobacco Control by all Parties to this treaty, as appropriate.
3. Progress in cancer control has been uneven. In spite of known effective interventions, the burden of cervical cancer, for example, remains greatest in low- and middle-income countries, where progress has been the slowest. While there have been moderate improvements in age-standardized cancer mortality rates in high-income countries, reaching a 25% reduction in some settings, overall declines in mortality from cancer have not been achieved globally.
4. Outcomes for childhood acute lymphoblastic leukaemia, a highly treatable cancer, reflect global inequities: 5-year survival is less than 20% in some low- and middle-income countries, as compared to 90% in select high-income countries. In many countries, women, children, indigenous groups, ethnic minorities and socioeconomically disadvantaged groups are often inequitably exposed to risk factors and have limited access to diagnosis and care services, which may result in poorer outcomes for these vulnerable groups.
5. The economic impact of cancer is significant and is increasing. In 2010, the total annual economic cost of cancer was estimated at approximately US\$ 1.16 trillion, threatening health budgets and economies at all income levels as well as causing financial catastrophe for individuals and families.

6. Effective cancer control planning requires accurate data, including reliable cancer registries and monitoring and evaluation programmes for quality assurance. While most countries (84%) have reported having a cancer registry, only one in five low- and middle-income countries have the necessary data to drive policy.

DEVELOPING AND IMPLEMENTING NATIONAL CANCER CONTROL PLANS

7. In the 2015 country capacity survey for noncommunicable diseases,¹ 87% of the 177 responding Member States reported having a policy, strategy or action plan for all or some cancers but only 68% reported that such a policy, strategy or action plan was operational. Implementing a national cancer control plan requires adequate resources, monitoring and accountability together with an effective health system, founded on the principles of universal health coverage and strong primary health care.

8. Orienting funding through domestic, bilateral and multilateral channels towards evidence-based, cost-effective interventions to reduce the risk factors, including tobacco use, unhealthy diet, physical inactivity and harmful use of alcohol, can reduce unnecessary expenditure on high-cost interventions, medicines and technologies. As recognized in the Addis Ababa Action Agenda,² resources for financing national cancer responses increasingly need to come from domestic budgets. According to some estimates, only 5% of global resources for cancer prevention and control are spent in low- and middle-income countries, despite the majority of preventable deaths occurring in these countries. Innovative financing is needed, including through increased taxes on tobacco and alcohol.

PREVENTION, EARLY DIAGNOSIS, SCREENING AND TREATMENT

9. Based on current knowledge, between one third and one half of all cancers are potentially preventable; this proportion will rise as further understanding of cancer risk factors and the development of associated preventive interventions is gained. Cancer is caused by a wide range of risk factors, including the four shared noncommunicable disease risk factors (tobacco use; unhealthy diet; physical inactivity; and harmful use of alcohol), obesity, infections, indoor and outdoor air pollution, radiation, environmental chemicals and occupational exposures. Tobacco use directly contributes to 22% of global cancer deaths. Cancer-causing infections are responsible for over 20% of cancer deaths in low- and middle-income countries. Vaccines are currently available for two of the most common oncogenic infectious agents, human papilloma virus and hepatitis B virus, and are very cost-effective strategies for cancer prevention.

10. Identifying cancer at the earliest possible stage means that treatment is less costly and cure is more likely. Late diagnosis of cancer is common in low- and middle-income countries, where many individuals present with advanced or metastatic cancer. Access to diagnostic, including pathology, and treatment services is limited in many low- and middle-income countries.

11. Cancer screening has had a limited impact in many low- and middle-income countries due to low participation, inadequate quality assurance measures and insufficient health infrastructure to deliver organized services. In 2015, only 20% of the countries that reported in the country capacity

¹ Assessing national capacity for the prevention and control of noncommunicable diseases: global survey. Geneva: World Health Organization; 2016.

² United Nations General Assembly resolution 69/313 (2015).

survey for noncommunicable diseases as having a screening programme achieved greater than 70% participation for cervical or breast cancer screening.

12. Of the estimated 20 million people who need palliative care each year, 6.6 million (33%) are cancer patients. Over half of cancer patients at all stages experience pain, even more so when undergoing treatment and when in advanced phases of disease, yet 83% of the global population live in countries with low or non-existent access to adequate pain management. In resolution WHA67.19 (2014) on the strengthening of palliative care as a component of comprehensive care throughout the life course, the Sixty-seventh World Health Assembly urged Member States to integrate palliative care services in the continuum of care, with emphasis on primary care, community and home-based care, and universal coverage schemes.

WHO'S RESPONSE

13. The Secretariat is supporting the fulfilment of the commitments made by Heads of State and Government in the Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases,¹ and the achievement of the Sustainable Development Goal targets pertaining to comprehensive cancer control. It is also supporting Member States in their efforts to develop, strengthen, implement and monitor national cancer control plans, and to prioritize cost-effective interventions in noncommunicable disease prevention and control.

14. The Secretariat has developed technical materials to support the planning and implementation of cancer prevention strategies by Member States. These include publications and activities to support the implementation of the WHO Framework Convention on Tobacco Control (2005) and provide guidance on interventions to promote healthy diet and physical activity (2014), reduce the harmful use of alcohol (2010) and implement vaccination programmes (2014). In addition, strategies have been developed on promoting cancer early diagnosis and screening (2007 and 2017), developing a comprehensive approach to cervical cancer control (2014), identifying priority medical devices (2016), strengthening palliative care services (2016) and analysing selected cost-effective cancer control interventions (2016). The 2015 update of the WHO Model List of Essential Medicines provides guidance on cancer medicines and treatment indications for 33 cancers and supports countries in negotiating lower medicine prices. Cancer control capacity is periodically assessed through the WHO global noncommunicable disease country capacity survey.

15. IARC, the specialized cancer research agency of WHO, has provided a global reference for cancer information through the Global Cancer Observatory, which is a web-based platform that uses data from several of IARC's key projects, including the GLOBOCAN project and the Cancer Incidence in Five Continents series of monographs. IARC leads the Global Initiative for Cancer Registry Development, which provides expertise, training and support to national authorities and cancer registries in low- and middle-income countries to address the lack of quality data. The IARC Monographs on the evaluation of carcinogenic risks to humans programme is the most comprehensive international approach for the evaluation and identification of carcinogenic agents. IARC conducts extensive research to evaluate screening methodologies with particular emphasis on technologies appropriate to low- and middle-income countries.

¹ United Nations General Assembly resolution 66/2 (2011).

16. A global joint programme has been developed by the WHO-led United Nations Inter-agency Task Force on the Prevention and Control of Non-communicable Diseases, with seven organizations of the United Nations system (IAEA, IARC, UNAIDS, UNFPA, UNICEF, the United Nations Entity for Gender Equality and the Empowerment of Women and WHO) providing support to governments to prevent and control cervical cancer. In addition, IAEA, IARC and WHO have been working together to provide support to countries in respect of comprehensive cancer control.

17. All WHO regional offices, and many country offices, have provided direct support to Member States in respect of cancer prevention and control by organizing regional workshops and training courses, convening meetings and passing resolutions. Some of the regional activities are described below.

(a) The Regional Office for Africa has been providing support for cancer prevention and control policies, strategies and plans in 19 Member States and has developed five normative documents on cancer prevention and control.

(b) The Regional Office for the Americas has developed five information products on cervical cancer to inform and provide direct in-country support for 11 Member States.

(c) The Regional Office for South-East Asia, in the light of the resolution on cancer prevention and control adopted by the Regional Committee for South-East Asia at its Sixty-eighth session (2015),¹ has been promoting activities to strengthen the early diagnosis, referral and management of cancers, focusing on primary care and on enhancing information systems and registries.

(d) The Regional Office for Europe has produced training materials for health professionals and in 2014 published a progress report for policy-makers on the prevention and control of noncommunicable diseases in the Region.

(e) The Regional Office for the Eastern Mediterranean has developed a regional framework (2016) and a regional strategy for cancer prevention and control (2009–2013).

(f) The Regional Office for the Western Pacific has supported workshops on leadership and capacity building for cancer control and, in partnership with a WHO collaborating centre in the Republic of Korea, has developed an e-learning course on the subject, based on WHO publications.

RECOMMENDED ACTIONS FOR MEMBER STATES AT THE COUNTRY LEVEL

18. **As part of the national commitments to develop policies and plans for the prevention and control of noncommunicable diseases, develop and implement a national cancer control plan with a focus on equity and access.** Countries should develop and implement national cancer control plans with adequate resources and accountability to provide high-quality, resource-appropriate cancer prevention and control services for all and the targets of the 2030 Agenda for Sustainable Development.

¹ Resolution SEA/RC68/R5 (2015) on cancer prevention and control – the way forward.

19. **Reduce risk factors for cancer through policies and programmes.** In accordance with existing global strategies to reduce the shared risk factors for noncommunicable diseases and multisectoral implementation of the WHO Framework Convention on Tobacco Control, cost-effective policies must be implemented to reduce the cancer burden, such as policies to: impose higher taxes on tobacco and alcohol; eliminate exposure to tobacco smoke or tobacco marketing tactics; restrict the marketing of foods and non-alcoholic beverages to children; ensure a quality public open space and adequate infrastructure for physical activity; reduce air pollution; and promote access to human papillomavirus vaccination. Research on the causes of human cancer and carcinogenesis is needed. Preventing the tobacco industry's interference in public health policy is a cross-cutting intervention critical for the success of reducing the risk factors of noncommunicable diseases.

20. **Improve access to timely diagnosis and treatment.** Pursuant to commitments made at the United Nations General Assembly in 2011, 2014 and 2015,¹ Member States should increase efforts to strengthen health systems at the national and local levels to ensure early diagnosis and accessible, affordable and high-quality care for all cancer patients. The implementation of comprehensive packages for noncommunicable disease prevention and control, such as WHO's Package of essential noncommunicable disease interventions for primary health care in low-resource settings,² can improve service delivery by promoting early diagnosis.

21. **Optimize the use of existing human resources and anticipate future requirements for cancer prevention and control.** Countries should ensure that their workforce has the appropriate competencies and skills for comprehensive cancer control through education and training programmes and appropriate recruitment, deployment and retention strategies, including career-development opportunities.

22. **Improve data to inform policy decision-making.** Effective policies must be founded on accurate data. In that respect, there is a need for renewed commitment to: the development and maintenance of population-based cancer registries; the surveillance of risk factors and of the measures implemented to control them; strengthened civil registration and vital statistics systems; routine health information systems that assess both technical and experiential quality; facility assessments to determine readiness and the quality of the services provided; and a rigorous monitoring and evaluation framework at the national and subnational levels.

ACTIONS FOR THE SECRETARIAT

23. The Secretariat will develop technical tools for and provide support to Member States in the planning, implementation, monitoring and evaluation of cancer prevention and control strategies, in the context of integrated national responses to noncommunicable diseases. This will include help with the costing of national cancer control plans, the implementation of cost-effective interventions including "best buys" in the context of the global action plan for the prevention and control of noncommunicable diseases 2013–2020, strengthening the workforce, promoting access to essential medicines and technology and integrating cancer prevention and control into national health systems. The Secretariat will also help to implement national cancer control plans and will provide in-country technical assistance as needed.

¹ United Nations General Assembly resolutions 66/2 (2011), 68/300 (2014) and 69/313 (2015).

² Implementation tools: Package of essential noncommunicable (PEN) disease interventions for primary health care in low-resource settings. Geneva: World Health Organization; 2013.

24. The Secretariat will also support efforts to strengthen the policy environment including the efforts by Member States to scale-up tobacco control, reduce the harmful use of alcohol, address environmental and occupational carcinogens, promote healthy diet and physical activity and increase human papillomavirus and hepatitis B vaccination coverage.

25. In addition, the Secretariat will support data collection and analysis, including through cancer registries, and the development of a monitoring and evaluation framework to assist with cancer prevention and control planning and quality assurance.

ACTION BY THE EXECUTIVE BOARD

26. The Executive Board is invited to consider the following draft resolution:

The Executive Board,

Having considered the report on cancer prevention and control in the context of an integrated approach,¹

RECOMMENDS to the Seventieth World Health Assembly the adoption of the following resolution:

The Seventieth World Health Assembly,

(PP1) Having considered the report on cancer prevention and control in the context of an integrated approach;

(PP2) Recognizing that cancer is a leading cause of death globally and a growing public health concern, with a projected increase in new cancer cases from 14.1 million in 2012 to 21.6 million annually by 2030;

(PP3) Acknowledging that there were 8.2 million cancer-related deaths worldwide in 2012, the majority of which occurred in low- and middle-income countries;

(PP4) Aware that certain population groups experience inequalities in risk factor exposure and in access to early diagnosis and treatment, and experience poorer outcomes from cancer;

(PP5) Noting the potential for the prevention of around half of all cancers through risk reduction;

(PP6) Aware that early diagnosis and prompt and appropriate treatment, including pain relief and palliative care, can improve the outcomes and quality of life of cancer patients;

(PP7) Acknowledging the limitations in access to medicines, technology and human resources for cancer care in low- and middle-income countries;

¹ Document EB140/31.

(PP8) Recalling resolution WHA58.22 (2005) on cancer prevention and control;

(PP9) Recalling also United Nations General Assembly resolution 66/2 (2011) on the Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases, which includes a road map of national commitments from Heads of State and Government to address cancer and other noncommunicable diseases;

(PP10) Recalling further resolution WHA66.10 (2013) endorsing the global action plan for the prevention and control of noncommunicable diseases 2013–2020, which provides guidance on how Member States can realize the commitments they made in the 2011 Political Declaration, including those related to addressing cancer;

(PP11) Recalling in addition United Nations General Assembly resolution 68/300 (2014) on the Outcome document of the high-level meeting of the General Assembly on the comprehensive review and assessment of the progress achieved in the prevention and control of non-communicable diseases, which sets out the continued and increased commitments that are essential in order to realize the road map of commitments to address cancer and other noncommunicable diseases included in the 2011 Political Declaration, including four time-bound national commitments for 2015 and 2016;

(PP12) Mindful of the existing monitoring tool that WHO is using to track the extent to which its 194 Member States are implementing these four time-bound commitments to address cancer and other noncommunicable diseases, in accordance with the technical note¹ published by WHO on 1 May 2015 pursuant to decision EB136(13) (2015);

(PP13) Mindful also of the WHO Framework Convention on Tobacco Control, an international public health treaty that was negotiated under the auspices of WHO and adopted by the Fifty-sixth World Health Assembly (2003) and entered into force in 2005, with 180 Parties committed to reducing the global burden of tobacco use;

(PP14) Mindful further of the Sustainable Development Goals of the 2030 Agenda for Sustainable Development, specifically Goal 3 (Ensure healthy lives and promote well-being for all at all ages) with its target 3.4 to reduce, by 2030, premature mortality from noncommunicable diseases by one third, and target 3.8 on achieving universal health coverage;

(PP15) Appreciating the efforts made by Member States and international partners in recent years to prevent and control cancer, but mindful of the need for further action,

¹ Available at <http://www.who.int/nmh/events/2015/technical-note-en.pdf?ua=1> (accessed 7 December 2016).

(OP1) URGES Member States:

- (1) to continue to implement the road map of national commitments for the prevention and control of cancer and other noncommunicable diseases included in United Nations General Assembly resolutions 66/2 (2011) on the Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases and 68/300 (2014) on the Outcome document of the high-level meeting of the General Assembly on the comprehensive review and assessment of the progress achieved in the prevention and control of non-communicable diseases, including the four time-bound national commitments for 2015 and 2016 set out in the Outcome document, in preparation for a third High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases, to be held in 2018, taking into account the technical note published by WHO on 1 May 2015, which sets out the progress indicators that the Director-General will use to report to the United Nations General Assembly in 2017 on the progress achieved in the implementation of national commitments, including those related to addressing cancer;
- (2) to integrate and scale up national cancer prevention and control as part of national responses to noncommunicable diseases, taking into account the 2030 Agenda for Sustainable Development;
- (3) to develop and implement national cancer control plans with adequate resources, monitoring and accountability;
- (4) to collect high-quality population-based data on cancer, including measurements of inequalities, through population-based cancer registries, household surveys and other health information systems to guide policies and plans;
- (5) to accelerate the implementation by States parties of the WHO Framework Convention on Tobacco Control, and encourage countries that have not yet done so to consider acceding to the Convention, given that substantially reducing tobacco use is an important contribution to reducing cancer;
- (6) to ensure the highest possible coverage of vaccination against human papilloma virus and hepatitis B virus, in line with the immunization targets of the Global Vaccine Action Plan 2011–2020 and in accordance with national priorities;
- (7) to develop, implement and monitor programmes for the early diagnosis and screening of cancers with an emphasis on common cancers, including cervical, breast and colorectal cancers, and with adequate capacity to avoid delays in diagnosis and treatment;
- (8) to develop and implement evidence-based protocols for cancer management and to ensure the availability of the essential medicines and technologies to implement them, through appropriate financing arrangements, measures to overcome patent barriers, quality assurance mechanisms, more effective supply systems and measures to reduce prices;

- (9) to promote recommendations that support clinical decision-making based on the effective, safe and cost-effective use of cancer diagnostic and therapeutic services, and facilitate the training of personnel based on independent information;
- (10) to mobilize domestic resources and consider innovative financing approaches, such as increasing taxes on tobacco and alcohol, to support cancer control and to ensure equitable access to cancer care;
- (11) to promote cancer research to improve the evidence base for cancer prevention and control;
- (12) to provide pain relief and palliative care in line with resolution WHA67.19 (2014) on the strengthening of palliative care as a component of comprehensive care throughout the life course;
- (13) to work towards the attainment of target 3.4 of the Sustainable Development Goals, reiterating the commitment to reduce, by 2030, premature mortality from cancer and other noncommunicable diseases by one third;

(OP2) REQUESTS the Director-General:

- (1) to develop guidance and tool kits to establish and implement comprehensive cancer prevention and control programmes;
- (2) to identify the most cost-effective interventions, and an investment case for cancer prevention and control, and to support their implementation at the country level;
- (3) to strengthen the capacity of the Secretariat to support the implementation of cost-effective interventions in countries and to work with international partners to harmonize the technical assistance provided to countries for cancer prevention and control;
- (4) to intensify collaboration with all stakeholders with the aim of scaling up cancer prevention and control and improving the quality of life of cancer patients;
- (5) to develop a public health and policy-oriented world report on cancer, based on the latest available evidence and international experience, with the participation of all relevant parts of the Secretariat, including IARC, and in collaboration with all other relevant stakeholders;
- (6) to report on progress made in implementing this resolution to the Health Assembly in 2021, through the Executive Board, as part of the report on progress made in the implementation of the global action plan for the prevention and control of noncommunicable diseases 2013–2020.

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A MEMBERSHIP ORGANISATION
FIGHTING CANCER TOGETHER

UICC Global Advocacy Report 2016



2016 Highlights

2016 has been an exciting year in the global health and development arena, with discussions around cancer prevention and control issues taking place at the highest levels including at the UN General Assembly Special Session on Drugs (UNGASS) and the Conference of the Parties (COP) to the WHO Framework Convention on Tobacco Control (FCTC). A highlight of the year for the cancer community has been the call for a new World Health Assembly (WHA) cancer resolution in 2017.

Key UICC activities and milestones include:

- **April:** UICC joined a side event at the UNGASS with the Australian government and was ably represented by Past-President Dr Mary Gospodarowicz. As part of a broader debate on the World Drug Problem, the side event reminded attendees of the need to keep balance in drug policies in mind, and drew attention to the global disparities in access to controlled medicines for medical purposes, with UICC highlighting the need to address opioids for palliative care for cancer patients.
- **May:** Landmark announcement by the AXA Group, one of the world's largest insurers, at a special event convened by UICC. Axa Group announced their decision to divest their tobacco industry assets, currently valued at 1.8 billion Euros, representing the first global commitment and establishing the Tobacco Free Portfolios Initiative.
- **July:** Joint UICC/NCD Alliance webinar for UICC members and the wider NCD community focused on emerging initiatives and resources to address NCD risk factors, with a focus on alcohol, physical inactivity and nutrition supported by expert presentations by member organisations.
- **November:** Joint launches of several key publications at the 2016 World Cancer Congress including the World Cancer Declaration Progress Report, *The Lancet* Series on health, equity, and women's cancers, with *The Lancet*, and the Arabic version of the 2nd Edition of The Cancer Atlas with Friends of Cancer Patients, the American Cancer Society and IARC, the International Agency for Research on Cancer.

Securing global commitments to prevent and control cancer

Update to Appendix 3 of the WHO Global NCD Action Plan 2013-2020

Appendix 3 of the Global NCD Action Plan is a menu of policy options to prevent and control NCDs that are classified as “very cost-effective and affordable interventions for all Member States”.

UICC and NCD Alliance participated in the online and in-person WHO consultations on the update to Appendix 3 of the WHO Global Action Plan for NCDs, which is due for adoption by Member States in May 2017. UICC pushed for inclusion of treatment recommendations and key updates, which we are pleased to report have been included, and we are optimistic that the new Appendix 3 will be approved by Member States. Importantly, there are now new recommendations to promote the treatment of early stage cervical, breast and colorectal cancer and a basic cancer palliative care package. In addition, new data were included to reinforce the cost-effectiveness of HPV vaccination as well as to extend guidance on cervical cancer screening and pre-lesion treatment.

Call for a World Health Assembly cancer resolution in 2017

In developing countries where the cancer burden is set to increase most rapidly, governments are urgently seeking best-practice guidance for implementation and scale up of phased, feasible and quality national cancer control programmes.

Achieving sustainable services with equitable access for timely cancer diagnosis and early and potentially curative treatment, which we know is cost-effective, is where help is most urgently needed. This was eloquently articulated earlier this year by Member States at UICC's co-hosted World Health Assembly side event, which concluded with a clear call for an updated cancer resolution in 2017 that would establish a clear framework for a health systems response for cancer.

The resolution would also:

- Reinforce WHO's mandate to respond to Member States' requests for assistance
- Provide a framework for international engagement
- Support and encourage alignment and integration with the WHO global strategies on women's, children's and adolescent's health, and life course and aging
- Bring together the components of recently adopted World Health Assembly Resolutions including those on palliative care, access to surgery and anaesthesia, and essential medicines

Coordinated by Jordan, a small group of Member States including Peru, Honduras, and Malaysia, sent a letter to the Chair of the WHO Executive Board in July, requesting that a cancer resolution be tabled as an agenda item at the January 2017 Executive Board Meeting in preparation for its formal adoption at the May 2017 World Health Assembly (WHA).

This call to action was echoed at this year's World Cancer Leaders' Summit and the UICC General Assembly, held in Paris in November 2016. A number of Member States have since expressed their support for a resolution and we have now have confirmation of its inclusion as an agenda item at the 140th WHO Executive Board Meeting. You can access a [draft of the resolution text](#) which was published on 29th December. UICC will be intensifying advocacy efforts over the coming months with the aim of supporting member and partner outreach to Ministries of Health in all regions. We will be providing template letters and outlining our key "asks" for the resolution to strive for the adoption of a comprehensive and robust cancer resolution in May 2017.



Dr Christopher Wild, Director International Agency for Research on Cancer, speaking at the UICC co-hosted side event at the World Health Assembly, 2016

Supporting a strong advocacy community

Developing the CAN25by25 Advocacy Network

Throughout 2016 we have continued efforts to engage UICC members by sending regular updates and calls to action to the CAN25by25 advocacy network, as well holding focus groups at the World Cancer Congress. We were delighted to see that over 2016, the CAN25by25 advocacy network has expanded from 87 to 109 members.

Supporting UICC member participation in key global fora

The Conference of the Parties (COP) to the WHO Framework Convention on Tobacco Control (FCTC) held its 7th session from 7th -12th November 2016 in New Delhi, India. This meeting brought together the WHO FCTC's 180 Parties – which includes almost every country in the world – to review the implementation of the FCTC and take action to promote its effectiveness.

In July 2016, UICC members from low- and middle-income countries who are involved in tobacco control activities were invited to submit applications for two travel grants to attend the COP7. In total 27 individuals from 19 countries applied and submissions were assessed based on the level of engagement and influence on tobacco control activities nationally. The two successful applicants were Mr. Zelalem Mengistu Abate, from Mathiws Wondu Ye-Ethiopia Cancer Society, and Prof. Mokhtar Hamdi Cherif, from Ennour Association, Algeria.

As part of the UICC delegation Mr. Abate and Prof. Cherif were provided with the opportunity to observe the COP7 negotiations, network with key actors in the field, and exchange knowledge with other members of the UICC delegation. *"We were able to gain a clearer understanding of the greatest barriers, including tobacco industry tactics, to implementation of the Convention for a number of Parties. This was a pertinent lesson for me given the current situation in my country [Ethiopia]"* said Mr. Abate.

Strengthening the role of UICC members in national and regional NCD Alliances

As a founding member of the NCD Alliance, UICC is committed to strengthening civil society efforts through the establishment of effective national and regional NCD Alliances that include strong cancer counterparts. Following a mapping exercise to assess the presence of UICC members in the 50+ national NCD Alliances, we organised a session at the World Cancer Congress to facilitate exchange between some of the UICC members already involved in Alliances and those interested in establishing or joining an existing national NCD Alliance. This was followed up in December 2016 with a series of one-to-one calls with UICC members in selected countries to develop a clearer picture of the role and capacity of UICC members in existing/emerging alliances, and willingness to further engage. UICC will continue collaboration with the NCD Alliance to build the capacity of national and regional Alliances in targeted countries in 2017.

Building the evidence base for national action

World Cancer Declaration Progress Report 2016

The World Cancer Declaration Progress Report marks the half way point between launch of the Declaration and the 2025 targets. For the first time, the 1000-strong UICC membership worked collectively to provide a unique civil society perspective on national successes and major challenges that remain to realise the World Cancer Declaration targets. It includes perspectives from 113 countries alongside a series of thematic pages highlighting resources and global initiatives that can help advance progress against each target.

The interactive online Report was launched at the World Cancer Leaders' Summit 2016 in Paris aligning with the Summit theme: *Our Journey to 2025*. We are delighted that the report has already been viewed over 400 times and we will be continuing to work with UICC members and partners to augment the online resource with case studies of national successes that can help inspire and support others.



Congress participants reviewing their national report at the World Cancer Congress in Paris

Access to essential medicines and technologies

UICC is continuing an advocacy focus on the disparity in access to treatment and care. Our work to support WHO in updating the cancer chapter of the Model Essential Medicines List (EML) in 2015 was reinforced with a further submission in December for the 2017 EML committee meeting. UICC has also continued its support to WHO to achieve a comprehensive consultation on access to technologies. The WHO guidance on Priority Cancer Technologies is also due to be published shortly and builds the body of guidance available to Member States to develop a cost-effective national treatment plans for cancer.

In addition, UICC continues to champion the investment case for treatment services. For example the team have been promoting the call to action in the *Lancet Oncology* commission – expanding global access to radiotherapy through an emerging partnership with ESTRO (European Society for Radiotherapy and Oncology). Supporting networks on key advocacy issues has been another area of work, with Dr Torode's invitation to speak at a Ministerial pre-conference at the 2016 African Palliative Care Conference in Uganda, UICC also provided a video statement on the importance and potential for developing palliative care services across the African region as a core component of any comprehensive national cancer response.

2017 Priorities

- Garnering support for a robust and comprehensive World Health Assembly Cancer Resolution in 2017, which will support the launch of the City Cancer Challenge 2025 (C/CAN for short)
- Developing joint monitoring tools and strengthening the capacity of national and regional NCD Alliances
- Development and launch of a campaign for the 2018 UN High Level Meeting on NCDs with a focus on the patient and healthcare worker perspective on access to cancer diagnosis, treatment and care.



To the Board of the Nordic Cancer Union
From Ragnheiður Haraldsdóttir, chairman
February 9th 2017

At a meeting of the board of the NCU in November 2016, it was decided to send the following questions to the six cancer leagues to share experiences and to provide a background for further discussions on the issues.

1. *How does your cancer society raise interest in cancer research in your country, e.g. in the grants you are offering? Can you stimulate financial support from other sources than your own?*
2. *How do you advertise and stimulate interest in the NCU grants?*

The responses are attached.

Ragnheiður Haraldsdóttir

How do the NCU cancer leagues stimulate interest in cancer research?

Sweden

Cancerfonden erfar inte att det brister i kännedom om att Cancerfonden är en betydande finansiär av svensk cancerforskning.

Det finns ett stort intresse i forskarsamhället och på universiteten att söka externa anslag. Detta gör att forskarna aktivt söker information om vilka anslag som finns att söka då detta är en förutsättning för att vara forskare i Sverige. Finansieringen från universiteten är så låg att ingen kan klara sin verksamhet utan att söka externa anslag.

Universiteten är också mycket aktiva genom sina s.k. "Grants Office" att regelbundet skicka ut information om vilka anslag som finns att söka och de erbjuder också stöd och råd för mer komplicerade ansökningar, typ EU och NIH.

Cancerfonden annonserar också i specialtidsskrifter när det är en aktuell ansökningsomgång. Den egna annonseringen bedömer dock inte Cancerfonden som den viktigaste kanalen för information utan det är universitetens interna arbete som mest effektivt når forskarna med information.

Av betydelse för att forskarna ska söka pengar från Cancerfonden är Cancerfondens goda anseende som en seriös forskningsfinansiär med en mycket diger process för bedömning av ansökningar baserat på projektens kvalitet. Principen om forskarinitierade projekt som söks i nationell konkurrens är av stor betydelse för Cancerfondens framträdande roll som en av de mest attraktiva forskningsfinansiärerna. Att ha ett anslag från Cancerfonden är en viktig kvalitetsstämpel för forskargruppen.

Att man söker finansiering även från andra finansiärer är en självklarhet i Sverige.

Finland

How does your cancer society raise interest in cancer research in your country, e.g. in the grants you are offering? Can you stimulate financial support from other sources than your own?

First, I would like to remind you that we have two independent organisations: Cancer Society of Finland and Cancer Foundation Finland sr. The latter does active fundraising and is the biggest and most important private funder of cancer research. As a part of the fundraising activities we tell to the general public and potential donors how we support cancer research. For example, we publish every spring a magazine called Focus Tutkimus. https://s3-eu-west-1.amazonaws.com/frantic/syopa-jarjestot/Focus_2016.pdf We also make videos of our researchers, for example, <https://www.youtube.com/watch?v=ffWSfGuRikw> <https://www.youtube.com/watch?v=-UXp6Xci9I4> <https://www.youtube.com/watch?v=i-mqzEH9ByU>

In future, we will do more. The Cancer Foundation Finland is celebrating its 70th anniversary in 2018. We will organise a special event for the researchers we fund and other stakeholders. We are also planning together with the Science Center Heureka a special interactive exhibition on cancer. It would take place in Finland in 2021 and then, we hope, travel to other Science Centers in the world.

We use as much as we can the earned media. That works well!

We are currently planning a joint research programme with the Academy of Finland <http://www.aka.fi/en> It will take place in this year and its name will be Big unsolved questions in health and chronic diseases. Our contribution is crucial for this programme to be launched.

How do you advertise and stimulate interest in the NCU grants?

Via the same channels as our own grants. However, not probably as systematically and broadly. There is an obvious need for improving the advertising.

Denmark

Kommunikationsafdeling

Fra Kommunikationsafdelingens side har vi fokus på kommunikationen til den brede offentlighed og har ikke nogen særskilte indsatser i forhold til at gøre opmærksom på de bevillinger, man kan søge via KB. Så vidt jeg tolker mailen nedenfor, er det den type kommunikationsindsats, der efterspørges. Hvis det er mere bredt at vække interesse for forskning og kræftforskning, så kan du måske nævne nedenstående eksempler fra Knaek Cancer, hvor vi på de sociale medier fortæller om de forskningsprojekter, pengene går til

<https://www.facebook.com/KnaekCancer/photos/a.156286754511900.35488.143327752474467/753689968104906/?type=3&theater>

<https://www.facebook.com/KnaekCancer/photos/a.156286754511900.35488.143327752474467/747506528723250/?type=3&theater>

<https://www.facebook.com/KnaekCancer/photos/a.156286754511900.35488.143327752474467/744091329064770/?type=3&theater>

Bevillingssektionen

Da Kræftens Bekæmpelse i mange år har annonceret vores bevillingsuddelinger på vores egen hjemmeside, er det kendt ude i forskningsmiljøerne, hvor de skal kigge efter vores uddelinger – herunder også NCU-midler: <https://www.cancer.dk/forskning/stoette-til-forskning/til-ansoegere/>

Derudover gør vi følgende med opslag for Kræftens Bekæmpelses Videnskabelige Udvalg KBVU, Kræftens Bekæmpelses Psykosociale Forskningsudvalg KBPF og vedrørende Knæk Cancer:

- ☐ Indsætter annoncer i relevante tidsskrifter som 'Ugeskrift for Læger', 'Magisterbladet', 'Dagens Medicin' og somme tider 'Psykolog Nyt'
- ☐ Sender annoncer til alle universiteter og fakulteter, som videreformidler annoncen på deres hjemmeside og på eventuelle tavler
- ☐ Sender annoncer til vores egen forskningsafdeling
- ☐ Gør vores kommunikationsafdeling opmærksom på, når der er et opslag, så de kan gøre opmærksom på det i nyhedsbreve eller i artikler.

Udvalgsmedlemmerne i vores faste videnskabelige forskningsudvalg formidler også budskabet i deres egne miljøer.

Iceland

1. *How does your cancer society raise interest in cancer research in you country, e.g. in the grants you are offering? Can you stimulate financial support from other sources than your own?*
2. *How do you advertise and stimulate interest in the NCU grants?*

Krabbameinsfélagið just recently (February 4th 2017 World Cancer Day) called for applications for scientific grants from the recently established Cancer Research Fund. This was advertised in the relevant local papers as well as on Facebook, and all stakeholders found there were "tagged". An association of those involved in cancer research in Iceland was also contacted.

The calls for NCU grants have been posted on our webpage www.krabb.is as well as sent to the Association of cancer researchers in Iceland.

The Faroe Islands

1. Vi informerer i pjecer, på hjemmesiden, altid når vi informerer om Krabbameinsfelagið og vores aktiviteter.

De penge, Team Rynkeby samler ind, administrerer vi også. Vi har ikke fået nogen ansøgning endnu, men har haft informationsmøder.

Udover det så informerer vi specielt:

Granskingarráðið (The Faroese Research Council), Ílegusavnið (Genetic biobank), Deildin fyri Arbeiðs- og almannaheilsu (Department of Occupational Medicine and Public Health) og Bjarni á Steig, overlæge på kræftafdelingen på Landssjúkrahúsið.

2. Stort set samme metode som i nr. 1.

Norway

1. How does your cancer society raise interest in cancer research in your country, e.g. in the grants you are offering? Can you stimulate financial support from other sources than your own?

Funding research is the main priority and the funding is an important supplement to public funding. NCS disseminate information and knowledge, along with initiating projects and supporting political advocacy campaigns. NCS is also actively involved in international projects. The NCS is dependent on fund raising and donations and runs several campaigns and fundraising events during the year to draw attention to current issues.

To mention some examples on how the NCS raise interest in cancer research:

- Political dialogue
- Launch event for the Open Call 2017
- Open Call 2017 Grant events – promoting the contribution of cancer research (for the public)
- Media/press – The NCS highlights questions of current importance and answers inquiries. The research projects also gets media coverage and our General Secretary is the front figure in many of the chronicles in Norwegian newspapers
- Cooperation meetings with universities and university hospitals
- Information on the web page of the NCS
- Via social media we give attention to some of the funded research projects
- Dialogue with other research financiers and authorities

2. How do you advertise and stimulate interest in the NCU grants?

- The Norwegian Cancer Society is in dialogue with the NCU Secretariat who publish information about the NCU Call on the NCU webpage

In addition, we provide information about the possibility to apply for funding:

- Email to researchers who have applied for or received funding from NCU
- E-mail to research institutions in Norway

- Send an invitation to the other secretaries general and their research sections to promote the announcement in their respective countries
- We also plan to inform the applicants who have applied for funding in the years 2015 – 2017 in the Norwegian Cancer Society's fifth Peer Review Committee in the Open Call (epidemiology, healthcare- and social science research)



To the Board of the NCU

From Ragnheiður Haraldsdóttir, chairman

February 6th 2016

NCUs cooperation with the Nordic Council and the Nordic Council of Ministers and the Bo Könberg report

The overall goal for the NCU is to *ensure best treatment for cancer patients, and implementation of effective cancer preventing initiatives in the Nordic countries* (the NCU General rules, 1st para.).

In 2012 the NCU initiated collaboration with the Nordic Council advocating for a stronger emphasis on health and cancer by the Nordic Council through the Faroese members of the Council.

From NCU annual report 2014: On the 30th of October 2013 the Nordic Council adopted a resolution concerning focus on long-term perspectives on cancer in the Nordic countries and cooperation between the NCU, the Nordic Council and the Nordic Council of Ministers (Medlemsforslag A 1582, Betænkning til A1582 og beslutning 10 og beslutning 11 til A 1582) on initiatives launched by the Nordic Cancer Union..... The NCU was very pleased that the resolution was adopted, and focused in 2014 on getting the resolution implemented in the Nordic Council of Ministers and in the health policies in each Nordic country.

In January 2014 the Westnordic Health Ministers and Bo Könberg, former health minister and governor in Sweden, had a meeting in the Faroe Islands, where the NCU chairman was invited to have a presentation on the NCU and benefits of strengthening Nordic cooperation in the field of cancer.

In April 2014 the Danish Cancer Society had a meeting with the secretariat of the Nordic Council of Ministers, where the benefits of nordic cooperation in the field of cancer were discussed. NCU recommended the Nordic Council of Ministers to focus on strengthening register research, specialized cancer care in the Nordic countries, a joint Nordic research education and joint Nordic clinical studies. The secretariat was positive towards a strengthened cooperation with the NCU.

After the meeting NCU sent its contribution to Bo Könberg's report on how nordic cooperation on health can be improved and strengthened over the next 5-10 years. Bo Könberg delivered his report to the Nordic Council of Minister's meeting on Iceland in June 2014. In connection with the report, representatives from the NCU were at a meeting with the Nordic Council concerning future cooperation on the field of cancer. The report is a step in the right direction concerning a joint nordic effort on cancer treatment and research in the Nordic countries.

The NCU is delighted that the organisation has succeeded in getting a closer cooperation with the Nordic Council and hopefully also with the Nordic Council of Ministers in the close future.

The NCU followed the progress of the relevant goals in the Könberg report, e.g. by inviting Anders Geertsen from the Nordic Council of Ministers to a NCU Board meeting in Finland in February 2015. At that meeting, the NCU expressed its disappointment with the lack of progress of the implementation of the Nordic Councils resolution and voiced its concern that the collaboration between the Nordic Council and the NCU on this issue was less than the NCU had anticipated, to the detriment of the cause of cancer patients in the Nordic countries.

Geertsen recommended that the member countries aimed their advocacy initiatives at the governments of the Nordic countries, as the Nordic council was not in a position to collaborate further with one patient group in the Nordic countries.

The NCU certainly is interested in following the advancement of the goals selected in the Könberg report and thus recently obtained an overview of the developments from the Nordic Councils secretariat (A. Gertsen), here attached.

Based on the above experience, the NCU might want to consider the next steps in advocating for and advancing the cause of cancer patients in the Nordic countries in line with its statutes and to reflect on the most effective approaches to reach its goals.

Ragnheiður Haraldsdóttir



Till

Kopia

Från

Ämne

Nordiska Ministerrådets sekretariat, Avdelningen Kunskap och Välfärd

Status för rapporten Det framtida nordiska hälsosamarbetet

Status för rapporten Det framtida nordiska hälsosamarbetet

Bakgrund

Under 2013 ombads den tidigare svenska ministern Bo Könberg genomföra en strategisk genomlysning av det nordiska hälsosamarbetet med förslag till hur detta kunde utvecklas i framtiden. Uppdraget gavs av de nordiska social- & hälsoministrarna och Nordiska Ministerrådets Generalsekreterare Dagfinn Høybråten. Syftet med genomlysningen var att presentera förslag till hur, och inom vilka områden av hälso- och sjukvård som samarbete kan förstärkas. Ambitionen var att förslagen skulle kunna genomföras inom 5-10 år.

Genomlysningen resulterade i rapporten *Det framtida nordiska hälsosamarbetet* med 14 konkreta förslag som i juni 2014 presenterades av Bo Könberg och Generalsekreterare Dagfinn Høybråten för det dåvarande isländska ordförandeskapet i Reykjavik. Rapporten går att finna [här](#).

Nordiska ministerrådet för social- och hälsopolitik (MR-S) diskuterade rapporten och dess samlade förslag vid sitt möte i oktober 2014. MR-S beslutade att påbörja uppföljningen av rapporten genom att inledningsvis fokusera på förslagen angående hälsoberedskap, högspecialiserad behandling, sällsynta sjukdomar, psykiatri och tjänstemannautbyte. Ministrarna noterade även att man ämnade diskutera förslaget om den stigande antibiotikaresistensen med sina ministerkollegor med ansvar för utrikes- och bistandsfrågor.

Vid efterföljande möten har social- & hälsoministrarna diskuterat och tagit beslut om att verkställa ytterligare initiativ mot bakgrund av förslagen i rapporten. MR-S planerar att behandla de återstående förslagen i rapporten vid sina möten de kommande åren.

Härmed följer information om aktuell status för rapportens förslag.



Status (januari 2017)

Förslag 1

Kraftfulla insatser mot den ökande antibiotikaresistensen

Minska konsumtionen av antibiotika i Norden till den lägsta europeiska nivån inom fem år.
Stark ekonomisk stimulans till forskning om ny antibiotika.

MR-S och MR-FJLS (Ministerrådet för fiskeri, havsbruk, jordbruk, livsmedel och skogsbruk) antog under 2015 en gemensam One Health deklaration mot antimikrobiell resistens. Till följd av deklarationen har Ministerrådet under 2016 tillsatt en tvärsektoriell One Health strategigrupp som ska stödja det nordiska samarbetet för att främja en låg nivå av antimikrobiell resistens och ett ansvarsfullt bruk av antibiotika i Norden. Denna grupp ska också använda det nordiska samarbetet för att stödja det internationellt koordinerade arbetet som pågår i EU, WHO, FAO & OIE.

Strategigruppen består av ämbetsmän både från human- och veterinärområdet med ansvar för antibiotikafrågor.

Gruppen har påbörjat sitt arbete under hösten 2016.

Förslag 2

Stärkt samarbete om högspecialiserad behandling i Norden

Etablera en nordisk beredningsgrupp på hög nivå för regelbunden dialog mellan länderna om behoven och möjligheterna för samlarbetsinitiativ på området.

MR-S har etablerat en Nordisk grupp (udvalg) för högspecialiserad behandling. Dess syfte är att ytterligare konsolidera och stödja nordiskt samarbete på området. Gruppen består av representanter från de Nordiska ländernas hälsomyndigheter.

Gruppen är nedsatt under 2 år (2016 och 2017) och ska rapportera för sitt arbete till ämbetsmannakommittén för social- och hälsopolitik (ÄK-S) vad gäller verksamheten under 2016 respektive 2017.

Förslag 3

Etablera nordiskt nätverk kring sällsynta diagnoser

Upprätta ett nätverk för framåtriktat samarbete kring sällsynta diagnoser för att stärka pågående och nya gemensamma insatser, samt bättre samordning av dessa.

MR-S har under 2016 etablerat ett nordiskt nätverk om sällsynta sjukdomar. Nätverkets syfte är att utveckla existerande och nya former för nordiskt samarbete om sällsynta sjukdomar, stärka nordiskt samarbete på området och förbättra koordineringen av gemensamma initiativ.



Nätverket är nedsatt under 2 år (2016 och 2017) och ska samarbeta med den nordiska gruppen om högspecialiserad behandling, som MR-S också har upprättat under 2016.

Nätverket ska rapportera för sitt arbete till ÄK-S vad gäller verksamheten under 2016 respektive 2017 och dessutom utarbeta rekommendationer till ÄK-S om nordiskt samarbete på området efter 2017.

Förslag 4

Skapa ett nordiskt virtuellt center för registerbaserad forskning

Stärk forskningssamarbetet kring dataregister, biobanker och kliniska interventionsstudier. Inför en modell för ömsesidigt erkännande av etikprövningar för nordiska forskningsprojekt.

Förslaget förväntas behandlas av MR-S vid dess möte våren 2017. Det norska ordförandeskapet 2017 har i sitt ordförandeskapsprogram för Ministerrådet inkluderat flera aktiviteter som relaterar till detta förslag.

Förslag 5

Ökat samarbete kring insatser för förbättrad folkhälsa

Öka erfarenhetsutbytet i folkhälsofrågor, främst vad gäller bruket av tobak och missbruket av alkohol

Förslag 6

En nordisk folkhälsopolitisk plattform för att minska ojämlikhet i hälsa

Skapa plattform för förslag till nordiska projekt och aktiviteter med målet att minska ojämlikhet i hälsa

MR-S har valt att behandla förslag 5 & 6 gemensamt och har under 2016 enats om att etablera en Nordisk folkhälsoarena med representanter på högre policyberednings- eller chefsnivå från departement/ministerier i länderna samt Färöarna, Grönland & Åland.

Arenan ska bidra till att stärka policyutveckling och implementering av åtgärder för en god och jämlik hälsa i de enskilda länderna bland annat genom att facilitera gemensamma utvecklingsprojekt om goda förebyggande och hälsofrämjande åtgärder.

Nordens välfärdscenter (NVC) fungerar som sekretariat åt Nordisk folkhälsoarena.

Den nordiska folkhälsoarenan ska inledningsvis fokusera på teman om ojämlikhet i hälsa, psykisk hälsa och alkohol, narkotika och tobak.

Förslag 7

Patientrörlighet inom Norden

Utvärdera effekterna för patienterna av de nordiska ländernas nyligen beslutade implementering av EU:s patientrörlighetsdirektiv, samt pröva att ytterligare vidga rättigheten för vård i annat nordiskt land.



Förslaget förväntas behandlas av Ministerrådet de kommande åren.

Förslag 8

Förstärkt samarbete om välfärdsteknologi

Ta fram gemensam nordisk definition och gemensamma riktlinjer för välfärdsteknologi med syfte att harmonisera standarder för välfärdsteknologiska produkter. Inkludera brukarna i utvecklingsarbetet.

Förslaget förväntas behandlas av Ministerrådet de kommande åren.

Det Nordiska statsministerinitiativet: "Nordiska lösningar på globala samhällsutmaningar" pågår under perioden 2017-2019. Här ingår flaggskeppsprojektet "Nordiska välfärdslösningar" som bland annat ska stärka export och gemensam internationell marknadsföring av innovativa nordiska välfärdslösningar, här under välfärdsteknologiska lösningar.

Förslag 9

Utökat samarbete om eHälsa

Fortsatt samarbete kring e-recept. Skapa ett nordiskt hälsobibliotek online och utveckla ett nordiskt sökverktyg för "Min patient".

Förslaget förväntas behandlas av Ministerrådet de kommande åren.

Förslag 10

Stärkt nordiskt samarbete inom psykiatriområdet

Skapa ett årligt återkommande nordiskt toppmöte inom psykiatriområdet, ökad kunskapsinsamling och erfarenhetsutbyte om modeller för bästa praxis.

Det danska ordförandeskapet arrangerade ett psykiatritoppmöte i Köpenhamn den 6:e november 2015 och det norska ordförandeskapet för ministerrådet 2017 planerar ett nytt toppmöte om psykisk hälsa under våren.

Ministerrådet har även tillsatt en nordisk arbetsgrupp på psykiatriområdet. Gruppen ska utforma ramarna för ett löpande nordiskt samarbete vad gäller insatser för människor med psykiska sjukdomar.

Förslag 11

Utökat mandat för samarbete inom hälsoberedskapsområdet

Ge utökat mandat till den existerande hälsoberedskapsgruppen (Svalbardgruppen) och inkludera alla aspekter inom ramen för ett nordiskt hälsoberedskapssamarbete.

MR-S har behandlat och godkänt ett utökat mandat för hälsoberedskapsgruppen. Mandatet träder i kraft den 1 januari 2017.



Förslag 12

Utbyggt nordiskt läkemedelsamarbete för högre kostnadseffektivitet och bättre säkerhet

Skapa gemensamt apotek för ovanliga läkemedel och utöka samarbetet kring sällsynta läkemedel. Öka informationsutbyte om inköpsavtal och om tillämpningen av nya läkemedel.

MR-S har behandlat förslaget så till vida att man beslutat att genomföra en kartläggning av ländernas erfarenheter på läkemedelområdet. Kartläggningen ska ses i sammanhang med det aktuella förslaget i rapporten *Det framtida nordiska hälsosamarbetet*. En arbetsgrupp ska presentera kartläggningen och rekommendationer om framtida samarbetsmöjligheter till ministerrådet under våren 2017.

Förslag 13

Nytt nordiskt tjänstemannautbyte (pilotprojekt 3 år)

Stärk det existerande avtalet för tjänstemannautbyte genom ett tillägg om kortare utbyten för tjänstemän som arbetar med hälsofrågor på berörda departement.

MR-S har valt att gå vidare med ett pilotprojekt om tjänstemannautbyte där korta utbyten kan genomföras för ämbetsmän från berörda departement. Pilotprojektet påbörjades i september 2015 och avslutades samt utvärderades under hösten 2016. Formerna för framtida tjänstemannautbyten behandlas i ministerrådet under våren 2017.

Förslag 14

Nordiskt samarbete om nationella experter i EU-kommissionen

Nytt informellt samarbete om placering av nationella experter i Europeiska kommissionen inom social- och hälsoområdet för en bättre användning av ländernas resurser.

Förslaget förväntas behandlas av Ministerrådet de kommande åren. Det finska ordförandeskapet för Ministerrådet 2016 har önskat att förslaget behandlas i sitt sektorprogram för 2016.