

# ANCR

Association of the Nordic Cancer Registries

*Annual Meeting in Malmö, Sweden*  
*September 2-4, 2014*



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# Meeting schedule

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## Tuesday September 2

10.30 - 17.00 ANCR Board meeting in Lund  
18.30 - Welcome reception with dinner and boule tournament at Boulebar

## Wednesday September 3

8.00 - 9.00 Registration  
9.00 - 10.30 Conference opening, keynote lecture and session 1  
10.30 - 11.00 Coffee break  
11.00 - 12.00 Session 2: Poster presentations  
12.00 - 13.00 Lunch  
13.00 - 14.30 Session 3  
14.30 - 15.00 Coffee break + "get ready for excursion"  
15.00 - 18.00 Excursion: Multicultural Malmö - a taste of food, culture and social innovation in Rosengård  
19.00 - Aperitif and Gala dinner at Sankt Gertrud. Entertainment from participants from each country is encouraged!

## Thursday September 4

9.15 - 10.30 Session 4  
10.30 - 11.00 Coffee break  
11.00 - 12.00 Session 5  
12.00 - 13.00 Lunch  
13.00 - 14.30 Session 6  
14.30 - 15.00 Coffee break  
15.00 - 16.00 Session 7  
16.00 - 16.15 End of conference

# Scientific programme

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## Wednesday September 3

- 9.00 Opening of ANCR conference 2014  
**Magnus Stenbeck.** Keynote lecture: New data protection regulation - a threat or promise?
- 9.15

### Session 1 CHAIR: Laufey Tryggvadottir

- 9.45 **1. Gerda Engholm**  
NORDCAN - comparable cancer statistics for the Nordic countries
- 10.00 **2. Eero Pukkala**  
Mapping cancer risk and related issues - Nordic experiences of using small-area based smoothing
- 10.15 **3. Katrín Ásta Gunnarsdóttir**  
On-line posters and other downloadable documents for presentation of data on the INCA platform
- 10.30 Coffee break

### Session 2 Poster presentations CHAIR: Mats Lambe

- 11.00 **4. Julie Buchholt Hebnæs**  
Human papillomavirus infection among 2460 men from Denmark: the DanMale study
- 5. Stefan Lönnberg**  
Cervical cancer incidence trends by morphology and region in Norway
- 6. Janne Pitkäniemi**  
Etiological age-components of cervical cancer in Finland in 1953–2011
- 7. Hrefna Stefánsdóttir**  
Finger length ratio (2D:4D), a possible marker of severe prostate cancer
- 8. David Robinsson**  
Risk of breast cancer for men on 5- $\alpha$  reductase inhibitors
- 9. Jianwei Zhu**  
Is cancer diagnosis associated with the subsequent risk of transient global amnesia?
- 10. Ingrid Glimelius**  
Late effects in the modern era of Hodgkin lymphoma treatment
- 11. Ruoqing Chen**  
Association between parental cancer diagnosis and child mortality - a population-based cohort study in Sweden
- 12. Jan Magnusson**  
Enhancing cancer registration using electronic methods: a pilot study among death certificate only (DCO) cases

**13. Maarit Leinonen**

What is the most feasible and efficient method to trace back of DCO cases?

**14. Randi Waage**

Upgrading to electronic reminders for screening for cervical cancer - effects on attendance and costs

**15. Tytti Sarkeala**

Breast cancer screening, lifestyle, and quality of life – Survey design and respondent selection

**16. Florian Al. Nicula**

Cervical cancer control and cancer registration in the North-Western Region of Romania

Session 3	CHAIR: Giske Ursin
13.00	<b>17. Sirpa Heinävaara</b> Overdiagnosis due to breast cancer screening - updated estimates of Helsinki Service Study
13.15	<b>18. Laufey Tryggvadottir</b> Effects of prognostic factors and treatment on survival in BRCA2 mutation carriers
13.30	<b>19. Sanna Heikkinen</b> Use of hair dyes increase the risk of breast cancer among Finnish women
13.45	<b>20. Marte Reigstad</b> Cancer Risk in Parous Women Treated with Assisted Reproductive Technology (ART) in Norway
14.00	<b>21. Anna Johansson</b> Prognosis following pregnancy-associated malignant melanoma (PAMM)
14.15	<b>22. Caroline Weibull</b> Does pregnancy trigger relapse in patients diagnosed with Hodgkin lymphoma?

**Thursday September 4**

Session 4	CHAIR: Eero Pukkala
9.15	<b>23. Malene Frøsig Svahn</b> Human Papillomavirus-associated cancer. Burden, trends over time and the role of social class
9.30	<b>24. Gry Baadstrand Skare</b> IMPACT OF HPV GENOTYPING IN TRIAGE AMONG WOMEN WITH ASCUS AND LSIL CYTOLOGY
9.45	<b>25. Miia Artama</b> Health behaviour predictors of non-participation in a mass screening programme for colon cancer in Finland

10.00	<b>26. Nea Malila</b> Sensitivity and maximal overdiagnosis in the randomized implementation of colorectal cancer screening in Finland
10.15	<b>27. Lingjing Chen</b>  Risk of disability pension among rectal cancer survivors – a Swedish population-based study with a focus on clinical determinants
10.30	Coffee break
Session 5	CHAIR: Magnus Stenbeck
11.00	<b>28. Hannah Bower</b> Assessing temporal trends in survival of acute myeloid leukemia patients using the loss in expectation of life
11.15	<b>29. Paul Lambert</b> Comparison of Different Approaches to Estimating Age Standardized Net Survival
11.30	<b>30. Karri Seppä</b> Long-term survival of cancer patients – what estimation method to use?
11.45	<b>31. Tor Åge Myklebust</b> Comparing methods for estimating and predicting net survival
Session 6	CHAIR: Hans Storm
13.00	<b>32. Göran Zetterström</b> Can indicators with target levels and a National assessment and evaluation increase adherence of National Guidelines in cancer care?
13.15	<b>33. Linn M. Åsli</b> Utilization of radiotherapy in Norway after implementation of The National Cancer Plan – a national population-based study
13.30	<b>34. Marianne Steding-Jessen</b> Routine administrative data as additional cancer registry source on primary cancer treatment in Denmark.
13.45	<b>35. Maarit Leinonen</b> Completeness and comparability of register data at the Finnish Cancer Registry
14.00	<b>36. Pär Stattin</b> Evaluation of data quality in the National Prostate Cancer Register of Sweden
14.15	<b>37. Jon Fridriksson</b> Lag Time to Adverse Events after Radical Prostatectomy and Curative Radiotherapy
14.30	Coffee break

Session 7	CHAIR: Nea Malila
15.00	<b>38. Kristina Kjærheim</b> Cancer risk in Nordic firefighters
15.15	<b>39. Yngvar Nilssen</b> Factors Influencing Survival and Patient Selection for Treatment in Lung Cancer Patients from Norway in the Period 1980-2011.
15.30	<b>40. Sandra Eloranta</b> Statistical cure and survival in Hodgkin lymphoma patients by clinical characteristics and treatment – a Swedish population-based study.
15.45	<b>41. Camilla Præstegaard</b> The impact of cigarette smoking on survival from ovarian cancer: A pooled analysis of 20 case-control studies.

# Session 1

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## 1. NORDCAN - comparable cancer statistics for the Nordic countries

**Gerda Engholm** 1, 2, *NORDCAN Group*

(1) *NORDCAN Secretariat*

(2) *Danish Cancer Society*

**Background** The Nordic cancer registries have since the 1970s collaborated on publications comparing incidence, survival etc., using ICD-7 codes for diagnosis. Some surprising results led to a detailed survey of national registration practice. From 2002 a joint Nordic cancer statistics database, NORDCAN ([www.ancr.nu](http://www.ancr.nu)), was launched with transformation of data following common international rules.

**Material and methods** The cancer statistics database for Denmark, Finland, Iceland, Norway, Sweden and the Faroe Islands is based on national data from Cancer Registers and Cause of death Registers. To ensure comparability the national registrations are transformed to ICD-O-3, and IARCcrgTools is used for check, transformation to ICD-10 and IARC/IACR rules for multiple cancers. Entities are groups that should be comparable over time. Similar transformations are made for mortality.

**Results** NORDCAN has evolved to a web-based database showing incidence, mortality, prevalence, relative survival, prediction etc. in tables and graphs available through a few clicks. Next update will include 2012-data for all countries. In spite of the big efforts to make comparable data, some problems still exist for cancer of the bladder, brain and nervous system and non-melanoma skin; problems which cannot be solved due to historical differences in criteria for registration between countries. Mortality data for pancreas and subtypes of leukemia is not available for the first years in some countries.

**Conclusions** In spite of big efforts at constructing comparable data between countries, some exceptions still exist. Problems are described in "The NORDCAN database" section in NORDCAN and further in the old survey from 2000.

2. Mapping cancer risk and related issues - Nordic experiences of using small-area based smoothing

**Eero Pukkala** 1, *Toni Patama* 1, and rest of NORDCAN team

(1) Finnish Cancer Registry, Institute for Statistical and Epidemiological Cancer Re

Lay people and health professionals are increasingly interested in health issues in their region. The high-quality cancer and population registries in the Nordic countries allow fine spatial and temporal visualization of mapped data. This presentation describes - with real-data examples - a mapping method developed in Finland for such visualization but also utilized for data from numerous other countries and non-cancer outcomes. The Finnish smoothing method is based on weighting small-area specific observations with population sizes and distance without losing the interpretability of the values. The approach has essentially improved the readability of spatio-temporal trends of incidence and mortality rates of cancers and has been applied in many studies. Other examples include demonstration of future projection of spatial patterns, illustration of survival outcome, rapidly changing health phenomenon (swine flu), and visual parallel comparison of changes in risk factor and disease incidence. With help of the tool, decision makers can understand the key message of existing data and use it more effectively in their efforts to provide better health care services. The method has been applied to all Nordic cancer data and integrated into the NORDCAN software. Examples of exciting cancer map animations from the latest NORDCAN update will be presented.

3. On-line posters and other downloadable documents for presentation of data on the INCA platform

***Katrín Ásta Gunnarsdóttir*** 1, *Anna Genell* 1

*(1) Regional Cancer Centre West, Western Sweden Health Care Region*

**Background** The INCA (information network for cancer care) platform has since 2007 provided a complete solution for hosting Swedish cancer quality registers, including facilities for everything from data-collection to real-time presentation of data within the system. The platform is currently home to more than 30 nationwide cancer quality registers and a growing number of quality registers in other areas of health care.

**Materials & methods** The integration in 2011 of the R statistical software solution on the INCA platform released a wealth of additional possibilities for presentation and analysis of data and the subsequent addition of the Sweave utility for R enabled weaving text, data and figures using LaTeX syntax. We applied these tools to produce document templates that can be populated with current quality register data at any given time. The resulting documents contain statistics, figures and text and are in the PDF format, which is the native format for documents created using Sweave and is widely available.

**Conclusion** Many different types of downloadable documents such as posters, slides, leaflets and reports can now be made available for aggregation and presentation of data on the INCA platform. Document templates can be defined for quality registries hosted on the platform and are, at the time of downloading, populated with current data for the unit in question (clinic, hospital and/or region), often including corresponding national data as a reference. The resulting documents can be easily printed or transferred to other media, facilitating presentation of data outside the INCA platform.

# Session 2: poster presentations

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## POSTERS

### 4. Human papillomavirus infection among 2460 men from Denmark: the DanMale study

**Julie Buchholt Hebnes** 1, Christian Munk 1, Bugge Nøhr 1, Ann Nielsen 1, Hans Ole Jørgensen 2, Thomas Iftner 3, Susanne Krüger Kjær 1,4

(1) Unit of Virus, Lifestyle and Genes, Danish Cancer Society Research Center, Copenhagen

(2) Danish Armed Forces Health Service Reserve, Denmark

(3) Medical Virology, Section of Experimental Virology, University Hospital of Tübingen

(4) Gynaecological Clinic, Juliane Marie Center, Copenhagen University Hospital, Denmark

**Background:** Human papillomavirus (HPV) can cause cervical cancer in women, penile cancer in men, and anal cancer and some head and neck cancers in both sexes. The epidemiology and natural history of HPV infection among women has been studied thoroughly whereas data on HPV prevalence among men representing the general population is highly needed.

**Material and methods:** Penile swab samples from 2460 male conscripts in Denmark were tested for HPV DNA using two tests, the Hybrid Capture 2 (HC2) and a polymerase chain reaction assay (PCR) Inno-LiPA. The overall, age-, and type-specific HPV prevalence with 95% confidence interval (CI) were estimated and the relationship between the two different HPV detection assays was assessed.

**Results:** The overall HC2 HPV prevalence was 22.2% (95% CI, 20.6–23.9) and 41.8% (95% CI, 39.9–43.8) as detected with LiPA. Of the LiPA-positive samples 51% were HC2-negative. We found 183 LiPA-positive samples that could not be genotyped (HPV-X) and of those, 88% (95% CI, 83.2–92.7) were HC2-negative. The most prevalent types were HPV51, HPV16, HPV66 and HPV6. High-risk and low-risk HPV prevalence peaked among men aged 20–29 whereas HPV-X prevalence increased with increasing age. HPV prevalence increased with increasing number of lifetime female partners although less strongly for HPV-X.

**Conclusions:** HPV is highly prevalent among the general male population in Denmark, HPV16 and HPV51 being the most prevalent. PCR detects twice as many positive samples as HC2 but also includes 18% HPV-X possibly representing cutaneous HPV types found on the normal genital skin.

## 5. Cervical cancer incidence trends by morphology and region in Norway

**Stefan Lönnberg** 1, *Bo Terning Hansen* 1, *Tor Haldorsen* 1, *Suzanne Campbell* 1, *Kristina Schee* 1, *Mari Nygård* 1

(1) *Cancer Registry of Norway*

Screening has been successful in reducing overall cervical cancer incidence but there are currently significant variations in disease burden between regions in Norway. Screening has consistently been shown to have a larger effect on squamous cell carcinomas (SCC) than on adenocarcinomas (AC), while both of these forms are causally related to persistent infection with oncogenic HPV. We analysed incidence trends over 50 years stratified by morphology in order to assess whether these variations can be explained by differences in preventive impact of screening or in background risk. All 19,530 cases of cervical cancer diagnosed in the period 1956-2010 were extracted from the cancer register. Based on registered morphology codes we classified 16,190 as squamous cell cancers (SCC), 2,048 as adenocarcinomas (AC), and 1292 as cervical cancers of other or unknown morphology. Trends in age-standardised incidence rates by morphology and region were modelled by join-point regression. The incidence of AC steadily increased in the observed period in all regions with an annual percentage change (APC) that varied from 1.0 (95% CI: 0.1-2.0) in Oslo to 2.4 (95% CI: 1.3-3.4) in the northern region, while the incidence trend of SCC diverged from the AC trend at a join-point in 1971-1975 followed by strong decreases in all regions. The estimated reduction in cervical cancer incidence due to screening was 70% overall with regional estimates from 60-75%. A relatively strong increase in AC in the northern region of Norway may reflect a greater exposure to HPV counteracting the preventive effects of screening.

## 6. Etiological age-components of cervical cancer in Finland in 1953–2011

**Janne Pitkaniemi** 1., Karri Seppä 1., Nea Malila 1., Matti Hakama 2

(1) Finnish Cancer Registry, Ins. for Statistical and Epidemiological Cancer Res

(2) School of Health Sciences, University of Tampere

**Background.** The objective of the study was to assess whether age incidence of cervical cancer in Finland is consistent with two etiological components.

**Material and Methods.** Study design was a population-based register study utilizing cervical cancer cases from the Finnish Cancer Registry covering female population of Finland and cases diagnosed at 20–84 years of age in 1953–2011. Age-specific incidence of cervical cancer was estimated by using a Poisson regression model with the assumption of two normally distributed latent components. A hierarchical Bayesian model was applied and life time net risks and crude numbers of cancer cases of the two components were estimated from the joint posterior.

**Results.** Before the screening started the life time net risks were 0.5% for younger and 1.3% for older (RR=0.43, 95% CI 0.29–0.61) with actual cases of 154 and 206 per year, respectively. The component of incidence occurring in younger women disappeared in 1970s after the organized mass screening program was initiated (in 1973–1977, RR=0.02, 95% CI 0.00–0.08). Since that, the risk for younger increased to 0.2% whereas the risk for older decreased to 0.5% in 2008–2011 (RR=0.58, 95% CI 0.25–0.94) with actual cases of 80 and 61 per year, respectively.

**Conclusions.** Existence of the two components is likely to be due to different etiological exposures. The trend in risk of the both components followed closely both the effects of organized screening and changes in sexual mores. The increase in the first is consistent with increase in HPV exposure.

7. Finger length ratio (2D:4D), a possible marker of severe prostate cancer

**Hrefna Stefánsdóttir** 1, **Helgi Jónsson** 2, **Anders Emmelin** 3, **Laufey Tryggvadóttir** 1, **Elínborg Jóna Ólafsdóttir** 1

(1) *The Icelandic Cancer Registry, Reykjavik, Iceland*

(2) *Faculty of Medicine, University of Iceland, Reykjavik, Iceland*

(3) *Social Medicine and Global Health, Lund University, Malmö, Sweden*

**BACKGROUND:** Prostate cancer is unusual in the sense that many prostate cancers are indolent and will not affect health, even without treatment. Therefore the common practice of PSA testing has resulted in much overdiagnosis. Studies are ongoing in hope to find markers that could contribute to a predictive model. The ratio between the length of the second and fourth finger (2D:4D) is fixed in utero and low 2D:4D indicates a high prenatal androgen action. Recent studies have reported an association between 2D:4D and risk of prostate cancer, indicating that it might be a possible marker for prostate cancer. We studied this association by linking data from the AGES-Reykjavik study with the Icelandic Cancer Registry.

**METHODS:** Data on 2,294 men (aged 67-96 years) were analyzed. Of these men 379 were diagnosed with prostate cancer. Regression models were used to estimate odds ratios (ORs) and hazard ratios (HRs), adjusting for potential confounders.

**RESULTS:** When comparing men with low digit ratio to men with high ratio overall prostate cancer risk was not significantly increased (OR 1.17; 95% CI 0.93-1.48), the risk of advanced cancer risk was increased (OR 1.68; 95% CI 0.97-2.92) and the highest risk was observed for death from prostate cancer with OR 2.43 (95% CI 1.02-5.78).

**CONCLUSION:** Finger length pattern might be a simple marker for advanced prostate cancer, men with index finger shorter than ring finger (low 2D:4D ratio) having an increased risk. If further studies confirm the trend seen in the results, 2D:4D finger ratio might be a marker that would contribute to a predictive model, helping with selection of treatment.

## 8. Risk of breast cancer for men on 5- $\alpha$ reductase inhibitors

**David Robinsson** 1,2, Hans Garmo 3, Pär Stattin 1

(1) Department of Urology and Andrology, Umeå, Sweden

(2) Department of Urology, Jönköping, Sweden

(3) Regional Cancer Centre, Uppsala, Sweden

Background: 5- $\alpha$  reductase inhibitors (5-ARI) are recommended for treatment of lower urinary tract symptoms (LUTS) due to prostatic enlargement. 5-ARI acts by inhibiting conversion of testosterone to 5-dihydrotestosterone (5-DHT). Some reports have indicated that 5-ARI may be associated with male breast cancer and the Food and Drug Administration (FDA) in USA has issued a warning concerning this risk. Material and methods: This cohort study was conducted within the Swedish population, from January, 2006 to December, 2008 with data on filled prescriptions from the Prescribed Drug Register and data from the Patient Register. The risk of breast cancer was assessed in men on 5-ARI, men on  $\alpha$ -blockers (another class of drugs for LUTS with no effect on hormonal levels), men who had undergone prostate surgery and among unexposed men. Results: Compared to unexposed men, men on 5-ARI had no increased risk of breast cancer, hazard ratios (HR) 0.69 (95% CI 0.25 - 1.90), whereas men on  $\alpha$ -blockers, HR 1.50 (95% CI 0.79 - 2.97) and prostate surgery, HR 1.87 (95% CI 1.00 - 3.52) had an increased risk. Conclusion: The hormonal milieu associated with prostatic enlargement as indicated by drug use or surgery is associated with an increased breast cancer risk. In contrast, the addition of 5-ARI and ensuing increases in testosterone levels and concomitant decreases in 5-DHT was not associated with an increased risk of male breast cancer. Our data indicate that the FDA warning on 5-ARI should be removed.

9. Is cancer diagnosis associated with the subsequent risk of transient global amnesia?

**Jianwei Zhu** 1,4, Donghao Lu 1, Katja Fall 2, Olafur Sveinsson 1, Fredrik Piehl 1, Unnur Valdimarsdóttir 3, Fang Fang 1

(1) Karolinska Institutet

(2) Örebro University Hospital,

(3) University of Iceland

(4) Shandong Provincial Hospital Affiliated to Shandong University

**Background:** Transient global amnesia (TGA) may be triggered by severe psychological stress. Whether a cancer diagnosis, a severely stressful life event, is associated with an altered subsequent risk of TGA has not been studied.

**Methods:** We conducted a prospective cohort study including 5,365,597 Swedes to examine the relative risk of TGA among cancer patients, as compared to cancer-free population in Sweden during 2001-2009. Incidence rate ratios (IRRs) derived from Poisson regression were used as estimates of the relative risks.

**Results:** As compared with cancer-free persons, the IRR of TGA among cancer patients was 0.98 (95% confidence interval [CI], 0.85 - 1.13) during the entire follow-up. The IRRs did not differ greatly according to time since cancer diagnosis or individual cancer types. No statistically significant association was observed when we stratified the analysis by age at follow-up; with the only exception noted for the group of 65-69 years (IRR, 1.31; 95% CI, 1.01 - 1.65).

**Conclusion:** Our study did not support the hypothesis that cancer patients have a higher risk of TGA than cancer-free individuals.

## 10. Late effects in the modern era of Hodgkin lymphoma treatment

**Ingrid Glimelius** 1, 2, Sara Ekberg 1, 3, Mats Jerkeman 4, Johan Linderöth 4, Martin Neovius 1, Sandra Eloranta 1, Karin Ekström-Smedby 1, ,

(1) Clinical Epidemiology Unit, Department of Medicine, Karolinska Institutet, Stock

(2) Department of Oncology, Radiology and Radiation Science, Section of Oncology, Up

(3) Department of Medical Epidemiology and Biostatistics, Karolinska Institutet, Sto

(4) Department of Oncology, Skåne University Hospital, Lund, Sweden

**Background** Despite the excellent cure rates in Hodgkin lymphoma (HL), survivors experience an increased risk of sick-leave/disability pension up to ten years post-diagnosis, not explained by HL relapse. The exact symptoms or complications causing this are incompletely known and our aim was to do a comprehensive search of long-term health care use and diagnoses among survivors. **Method** We identified 1456 HL-patients aged 18-60 (mean 34) years at diagnosis in the Swedish Cancer Register 1992-2009, and 5824 age- and sex-matched population comparators. Hospitalization rates and diagnoses for patients/comparators were retrieved from the national patient register 1-16 years post-diagnosis. Incidence rate ratios (IRR) for hospitalization were calculated in a negative binomial regression model. **Results** The hospitalization rate was doubled for relapse-free HL-patients versus comparators: IRR=1.87, 95%CI 1.63-2.14 as was the rate of outpatient visits (excluding regular HL-control visits): IRR=2.13, 95%CI 1.94-2.34. Comparing proportions of hospitalizations/visits by diagnostic ICD10 groups, malignancies other than HL were more common among patients than comparators during the entire follow-up, while cardiovascular and respiratory disease were more common after the 10th year. Patients experienced less psychiatric diseases during follow-up than comparators. **Conclusions** Relapse-free HL-patients have more hospitalizations and outpatient visits than comparators. In early years after diagnosis, visits due to malignancies (other than HL) were increased for survivors, indicating both increased susceptibility and treatment complications. From the 10th year post-diagnosis and onwards diseases of the circulatory and respiratory systems were overrepresented among survivors versus comparators, likely reflecting late treatment-complications.

11. Association between parental cancer diagnosis and child mortality - a population-based cohort study in Sweden

**Ruoqing Chen** 1, Arvid Sjölander 1, Unnur Valdimarsdóttir 2, Catarina Almqvist 1,3, Weimin Ye 1, Katja Fall 4, Kamila Czene 1, Fang Fang 1,

(1) Department of Medical Epidemiology and Biostatistics, KI, Stockholm, Sweden

(2) Center of Public Health Sciences, University of Iceland, Reykjavík, Iceland

(3) Lung and Allergy Unit, Astrid Lindgren Children's Hospital, Stockholm, Sweden

(4) Clinical Epidemiology and Biostatistics Unit, Örebro University, Örebro, Sweden

Background: Cancer diagnosis is known to induce severe psychological stress for patients; however, how it affects the next-of-kin is less well documented. This study aimed to assess the impact of parental cancer diagnosis on the risk of childhood death. Materials and Methods: A population-based cohort study was conducted using the Swedish National Registries, including 2,871,973 children followed during 1991-2009. Parental cancer diagnosis during follow-up was defined as a time-varying exposure. We used Cox proportional hazards regression to calculate the hazard ratio (HR) and its corresponding 95% confidence intervals (CI) as an estimate of the association between parental cancer and childhood mortality. We adjusted for attained age, sex, gestational age, mode of delivery and birth weight of the children, maternal age at child's birth, as well as educational level and socio-economic status of the parents in the analyses. Results: During follow-up, 127 deaths occurred among children with parental cancer and 4381 among the unexposed children. Among younger children (aged 1-12), an increased risk was only noted for death due to cancer (HR: 2.04; 95% CI: 1.12 – 3.72). Among adolescents (aged 13-18), an increased risk was noted for childhood death in general (HR: 1.52; 95% CI: 1.24 - 1.86), and for both non-cancer-related (HR: 1.43; 95% CI: 1.15 - 1.79) and cancer-related (HR: 2.04; 95% CI: 1.31 – 3.20) causes. Conclusion: Our results indicate that children, particularly adolescents, have a higher mortality risk before 18 years of age if they have a parent diagnosed with cancer after one year of age.

## 12. Enhancing cancer registration using electronic methods: a pilot study among death certificate only (DCO) cases

**Jan Magnusson** 1, *Maarit Leinonen* 1, *Kaius Perttilä* 1  
(1) *Finnish Cancer Register*

**Background:** The proportion of death certificate only (DCO) cases is a commonly used criterion to judge completeness of cancer registration. This proportion can be reduced by efficient trace back of DCO cases. We have designed a feasibility study to test logistics of on-line entry of clinical notification. The aim is to increase the completeness of cancer register data, improve data quality and reduce the part of manual handling and thereby costs related to the process.

**Material & Methods:** FRC receives notifications on cancers patients from different sources. In year 2012 approx. 1500 cancer cases first came to the attention of the FCR via death certificates. These patients are individually linked with the Care Register for Health and Welfare (HILMO) and the Register of Primary Health Care Visits (AvoHILMO) to obtain information on the health care providers prior to their death. This information is used as a basis for sending out reminders using pre-filled tailored clinical notifications forms. Collection process of data: The new electronic registration of the data will be based on a secure web based on-line data entry system replacing the previously used electronic or papers based off-line solutions.

**Results:** Process description and an on-line demonstration of the solution will be presented at the meeting.

**Conclusions:** This pilot study will demonstrate whether the completeness and register data quality can be increased by sending targeted electronic reminders for DCO cases. Also, it will guide us in our way into the electronic ages with more accurate and timeliness data collection in the FCR.

13. What is the most feasible and efficient method to trace back of DCO cases?

*Minna Merikivi 1, Susanna Mustonen 2, Irma Ovaska 3, **Maarit Leinonen 4***

*(1) Cancer Society of Finland/Finnish Cancer Registry*

*(2) Cancer Society of Finland/Finnish Cancer Registry*

*(3) Cancer Society of Finland/Finnish Cancer Registry*

*(4) Cancer Society of Finland/Finnish Cancer Registry*

Background: Initially, 47% of new incident cancer cases are registered without clinical information. Approximately 13 000 reminders have been sent every year of which around 58% receives some kind of response. Death certificates mentioning cancer are received from the Statistics Finland. These may not include information on a hospital of cancer diagnosis or that of treatment. Uncertainties in death certification makes death certificate only (DCO) cases an attractive target for interventions aiming to improve quality in registration. Material & Methods: Around 1500 cancer cases registered in 2011 and 2012 first came to the Finnish Cancer Registry's attention via a death certificate. Among DCO-2011 cases we elaborated on patients whose death had been notified by joint authorities. Home municipalities for 178 DCO-2011 cases were investigated and a reminder was sent to a main health center. DCO-2012 cases were individually linked with two health care registers to obtain information on a service provider prior to their death and all possible records with cancer diagnosis ever. This information was used as basis for sending out electronic reminders. Results: 78% of reminders that had been sent to a main health center of patient's home municipality came back. Of these, 94% had sufficient information on treatment. Results from a pilot study using electronic reminders for DCO-2012 cases will be compared to these proportions. Conclusions: The completeness and validity of cancer register data can be improved by sending reminders to the main health center of patient's home municipality. It needs to be assessed whether utilizing information from other health care registers and sending out electronic requests will further improve quality.

14. Upgrading to electronic reminders for screening for cervical cancer - effects on attendance and costs

**Randi Waage** 1, *Gry Baadstrand Skare* 1, *Kristin Hoel Brenden* 1, *Stefan Lönnberg* 1  
(1) *The Cancer Registry of Norway*

Background: In autumn 2012 The Cancer Registry entered into collaboration with Digipost in order to send screening reminders to registered electronic mailbox users. Materials and methods: We followed the number of letters sent through Digipost throughout the period October 2012 to January 2014. Reminders, second reminders and reminders about lack of follow up after unsatisfactory tests were included. The cost of a regular reminder was 7 NOK. Electronic reminders cost 2 NOK with a surcharge of 0.5 NOK for SMS notification. We also followed screening attendance within 6 months after receiving either an electronic or a regular reminder. Results: In October, November and December 2012 2 786 (3.5%) out of 78 697 reminders were sent by Digipost. In the first six months of 2013 the percentage had increased to 4.4% and during the second half year to 4.8%. . The participation rate was 33% after regular and 40% after electronic reminders. The cost per participating woman was thus 21 NOK for regular and 6 NOK for electronic reminders. Conclusion: Using electronic reminders increases the attendance and reduces the costs.

## 15. Breast cancer screening, lifestyle, and quality of life – Survey design and respondent selection

**Tytti Sarkeala** 1, *Sirpa Heinävaara* 1, *Nea Malila* 1, 2

(1) *Finnish Cancer Registry*

(2) *Tampere University*

**Background.** Few surveys have integrated breast cancer screening, lifestyle, and quality of life. Survey researchers are concerned with potential bias in estimates generated from the surveys. **Objectives.** To describe the design of the Finnish population-based survey, and to evaluate the level of bias among the respondents from the first two survey rounds.

**Material & method.** Questionnaires focusing on lifestyle-related risk factors, quality of life, and breast cancer screening were sent to 10 000 women in 2012-13, one year before their first invitation to screening. Corresponding materials will be re-mailed in 2014-15. The target population was randomly drawn from the Finnish National Population Registry (FNPR). The data included birth year, marital status, municipality, and information on children. Data on education was derived from the Statistics Finland (SF). We calculated response rates, and number of respondents and non-respondents in the eligible survey population, and assessed survey response by characteristics derived from the FNPR and the SF. We also examined the impact of non-response on the Satisfaction With Life Scale (SWLS).

**Results.** The survey response rate in 2012-13 was 52.4%. Compared to the non-respondents, the respondents were more often married, academically educated, and native speakers. Nevertheless, the native speakers and the less educated formulated a small proportion of the eligible study population. Therefore, the estimates of SWLS among the survey respondents were in line with those corrected by non-response among the eligible study population.

**Conclusions.** Based on the SWLS, the respondents of the Finnish population-based survey may well represent the eligible study population.

## 16. Cervical cancer control and cancer registration in the North–Western Region of Romania

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**Background.** The Oncology Institute in Cluj-Napoca, Romania, hosts the Cervical Cancer Screening Program Regional Management Unit since 2002, and the North-Western Regional Cancer Registry (NWRRCR) since 2008. In 2014, this institution started a project with the Cancer Registry of Norway: *CerCcRom* - Cervical Cancer Control for Roma and Other Disadvantaged Groups (RODG) in North-Western Region of Romania (NWRRCR). The overarching aim of the project is to improve life and wellbeing of specific groups of women at high risk of cervical cancer.

**Material&methods.** The *CerCcRom* project has the following specific objectives:

1. To study access barriers to cervical cancer screening of the RODG;
2. Build institutional capacity for improving cancer registration completeness and quality within the NWRRCR, including issues related to information technology;
3. Pilot test the feasibility and suitability of implementing HPV as a primary screening tool in the cervical cancer screening program (currently using Pap smears).

**Results.** We expect: a) to increase awareness amongst the RODG women in the target area regarding cervical cancer risk factors; b) improve the existing strategies and methods available for cervical cancer prevention and detection; c) to increase access and participation rates to periodical screening; d) improve timeliness, completeness and quality of the NWRRCR data, and e) on long term, reduce cervical cancer incidence and mortality amongst all women in the region, and in particular amongst the RODG women, as inferred from high quality data from the NWRRCR.

**Conclusions.** The *CerCcRom* project will address and hopefully solve issues related to cancer prevention strategies and cancer registration. Existing cervical cancer screening strategies using Pap smear will be changed to the use of HPV testing as primary screening tool. We hope to increase access and participation of disadvantaged groups of women at high risk for cervical cancer, and will assist designing regional programs and policies from social justice perspective.

\*The research leading to these results has received funding from EEA Financial Mechanism 2009-2014 under the Project Contract no 6SEE/30.06.2014

# Session 3

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## 17. Overdiagnosis due to breast cancer screening - updated estimates of Helsinki Service Study

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**Background** Overdiagnosis is one of the possible adverse events of breast cancer screening with the estimates ranging from 0% to 50%. We updated the estimates of overdiagnosis in Helsinki service screening study.

**Material and methods** Women aged 50-59 years have been invited to Helsinki service screening since 1986. The incidence of breast carcinoma and invasive breast cancer in 1975-2011 were analysed among the first 5-year birth cohort invited to screening and three older 5-year non-invited birth cohorts using Poisson regression. The incidence of invasive breast cancer was also analysed by stage. Expected incidence without screening in the first 5-year birth cohort was calculated using two alternative approaches. The overdiagnosis was assessed by comparing the observed and expected cumulative incidence of breast carcinoma and invasive breast cancer.

**Results** Overdiagnosis of breast carcinoma and invasive breast cancer were close to each other. The estimates of overdiagnosis were largest for the localized invasive breast cancer. Results were not dependent on the approach of estimating expected incidence.

**Conclusions** Our estimates of overdiagnosis are in line with the other plausible estimates in Europe (1-10%).

## 18. Effects of prognostic factors and treatment on survival in BRCA2 mutation carriers

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**Background** Mutations in the BRCA2 gene are associated with a highly increased risk of breast cancer. Around 150 mutation carriers are diagnosed with breast cancer in the Nordic countries every year. However, little is known of specific effects of prognostic factors and treatment on survival among those patients.

**Material & methods** We combined data on mutation status from three sources in Iceland and compared the risk of breast cancer-specific death according to treatment and status of prognostic factors between 288 female patients carrying an Icelandic BRCA2 founder mutation and 623 matched noncarriers diagnosed in 1935-2013. Hazard ratios (HRs) were estimated for breast cancer-specific death using Cox regression.

**Results** A positive versus a negative ER status was associated with an increased risk of death (univariate analysis) among mutation carriers (HR=1.57 (0.93-2.66)) contrary to noncarriers (HR=0.71 (0.46-1.08)), for interaction  $p=0.02$ . BRCA2 mutation carriers had an increased risk of breast cancer death compared with noncarriers (HR=1.48 (1.06-2.08)) after adjusting for year of birth and diagnosis, tumour size, nodal stage, ER and PR receptors. In the subgroup receiving adjuvant chemotherapy the HR comparing carriers with noncarriers was 1.08 (0.67-1.75) whereas for patients not administered adjuvant chemotherapy the HR was 2.94 (1.74-4.94). For women receiving Tamoxifen HR= 2.23 (1.18-4.23) and HR associated with no Tamoxifen use was 1.62 (1.04-2.50).

**Conclusion** A positive ER status predicts adverse outcome among mutation carriers and Tamoxifen use does not appear to confer a survival advantage among them, contrary to what is found for women not carrying BRCA2 mutations.

## 19. Use of hair dyes increase the risk of breast cancer among Finnish women

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**Background** It has been presumed that certain aromatic amines, such as 4-aminobiphenyl (4-ABP), may play a role in the etiology of breast cancer. Remnants of 4-ABP has been detected in commercial hair dyes, even if its use as a compound of cosmetic products is prohibited. The aim of this study was to estimate the level of association between self-reported use of hair dyes and the risk of breast cancer.

**Material and methods** The study was a retrospective, population-based case-control study, research material consisting of a questionnaire data to 8 366 Finnish breast cancer patients, aged 22-60 and diagnosed in 2000-2007 and 35 354 age-matched controls. As a measure of association, univariate and multivariate odds ratios from the logistic regression model applied to the frequency matched sets of cases and controls are reported.

**Results** The relative risk of breast cancer increased by 24% (OR: 1.24, CI 95% 1.10-1.39) with any use of hair dyes, after adjusting for other major risk factors. A significant increase in the risk of breast cancer with increasing cumulative use of hair dyes was observed. The attributable fraction of hair coloring on breast cancer was 19.4% (95% CI: 9.1-28.1).

**Conclusions** Use of hair dyes increased the risk of breast cancer independently. Even if the risk effect is moderate, its' impact on public health is significant due to vast popularity of hair coloring in modern societies. The findings suggest that excessive exposure to hair dye compounds should be avoided. Also, the current practice of self-regulation of the cosmetic industry is challenged.

## 20. Cancer Risk in Parous Women Treated with Assisted Reproductive Technology (ART) in Norway

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**Introduction:** The effects of hormone treatment in ART regarding cancer risk have been studied extensively, but results are inconsistent. **Aim:** The aim of this study is to compare the risk of cancer in women who gave birth following ART to that in women who gave birth following natural conception.

**Method:** The cohort consists of 809 006 women registered in the Medical Birth Registry of Norway (MBRN) as having given birth between January 1st 1984 and December 31st 2010. 16 629 women gave birth to one or more children following ART. Data from the MBRN are linked to the Cancer Registry of Norway by personal identification numbers, obtaining all cancer cases. Cox regression analysis is used to compute hazard ratios between ART women and controls; for any cancer, and for breast, cervical, ovarian, uterine, colorectal, central nervous system, thyroid cancer and malignant melanoma. 22 434 cohort members had a cancer diagnosis, 346 ART women and 22 088 controls.

**Results:** Analysis of cancer at all sites for ART women compared to controls gave an HR of 1.09 (95% CI 0.98-1.22). For women receiving in-vitro fertilisation (IVF) only, HR was 1.22 (95% CI 1.01-1.48) for breast cancer and 1.69 (95% CI 1.13-2.54) for CNS cancers, compared with controls. For ART women followed for >10 years, HR was 1.33 (95% CI 1.05-1.68) for breast cancer.

**Conclusion:** The elevated risk of breast and CNS cancers in subgroups of infertile women stresses the importance of continued monitoring of women treated with assisted reproductive technology.

## 21. Prognosis following pregnancy-associated malignant melanoma (PAMM)

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(4) *Regional Cancer Centre, Uppsala, Sweden*

**Background:** Malignant melanoma (MM) is one of the most common malignancies in young women. It remains debated whether a MM diagnosed during pregnancy or lactation has a poor prognosis. We aimed to study if tumor location, stage at diagnosis and prognosis differ between women with pregnancy-associated malignant melanoma (PAMM) and women diagnosed with MM not near a pregnancy (non-PAMM).

**Material & Method:** We identified all women with MM aged 15 to 44 years at diagnosis in the Swedish Cancer Register between 1963 and 2009 (n=6,857). Information on reproductive history was obtained from the Multi Generation Register. Data on educational level and vital status were retrieved from the Education register and the Cause of Death Register, respectively. We defined PAMM to include MMs diagnosed during pregnancy and up to 2 years after delivery (n=1,019). Using flexible parametric survival models, we estimated hazard ratios (HR) for cause-specific mortality in the two patient groups adjusted for age, period, parity, education and tumour location.

**Results:** Overall, women with PAMM and non-PAMM did not differ with regard to tumour location and stage at diagnosis-. Moreover, there was no increased mortality in women with PAMM compared to women with non-PAMM (adjusted HR=1.09, 95%CI 0.83-1.42), with the possible exception of women diagnosed during the 2nd year postpartum (adjusted HR=1.42, 95% CI 0.98-2.06).

**Conclusion:** Overall, the cause-specific mortality in women with PAMM did not differ from that in women with non-PAMM.

22. Does pregnancy trigger relapse in patients diagnosed with Hodgkin lymphoma?

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**BACKGROUND** Hodgkin lymphoma is relatively common in young women, so the implications of the disease and its treatment on childbearing must be taken into account. Modern treatments are less gonadotoxic than in the past, and overall survival has improved considerably, resulting in an increasing number of HL survivors considering pregnancy. Despite a lack of empirical evidence, clinicians and patients are concerned that there is an association between pregnancy and relapse, which discourage women in remission from HL from getting pregnant.

**METHODS** We will utilize data from the Swedish lymphoma register, supplemented with data abstracted from medical records and matched with the Medical birth register. We will have comprehensive data on disease, treatment, and patient characteristics for women diagnosed with HL from 1992-2009. Women will be followed from date of remission until date of relapse. The time-varying exposure of interest is pregnancy, measured in terms of delivery of a child. Relative risks of relapse will be estimated using a flexible parametric model.

**RESULTS** The data set has been assembled and analysis commenced but no results are available at this stage. Results will be presented at the meeting. The potential for bias due to a 'healthy mother effect' is a concern, so we will perform extensive sensitivity analyses before making any results public. Our analysis data consists of close to 500 women diagnosed 1992-2009 who were less than forty at diagnosis.

# Session 4

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## 23. Human Papillomavirus-associated cancer. Burden, trends over time and the role of social class

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**Background.** Changing sexual habits have been proposed to influence the development of HPV-associated cancers (HPVaC) and its precursor lesions. We therefore wanted to explore incidence trends for HPVaC according to time and birth cohort. Furthermore we wanted to address whether a social inequality exists in the burden of HPVaC in the most recent years.

**Material and methods.** Cancer cases of the cervix, vagina, vulva, anus, oropharynx and penis diagnosed from 1978-2011 were identified from the Danish Cancer Registry whereas the precursor lesions were identified using the Danish Pathology Data Bank. To visualize trends, age standardized incidence rates (ASRs) were estimated according to sex, period and birth cohorts. The relative risks for incident cases of HPVaC in the most recent period from 2009-2011 for different social classes were calculated using data on education and disposable income from Statistics Denmark.

**Results.** The incidence of anal and oropharyngeal cancer increased through the last three decades, mainly in individuals born after 1935. For vaginal and cervical cancers a decreasing trend in ASR was observed although this leveled off in women born after 1945. The ASRs for all HPVaC combined stratified according to sex showed a marked decrease for women and an increase for men. Differences according to education and income will be presented at the meeting.

**Conclusion.** The change in ASR for HPVaC mainly seen in individuals born after 1935 could be compatible with the changing sexual habits and practices in the 1960'ies. The burden of HPVaC in men is approaching that seen in women, mostly due to an increase in oropharyngeal cancers.

## 24. IMPACT OF HPV GENOTYPING IN TRIAGE AMONG WOMEN WITH ASCUS AND LSIL CYTOLOGY

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**Aims:** To estimate the predictive values of HPV DNA genotyping in triage among Norwegian women aged 25-69 with ASCUS and LSIL cytology.

**Methods:** From July 2005 until June 2010 6803 HPV analyses were performed as follow-up tests for 6059 women with screening-detected ASCUS or LSIL cytology in Health Region South/East Norway. HPV DNA detection was performed with HybridCapture II (Qiagen) and genotyping with in-house nmPCR(1). All HPV analysis results are registered in the screening databases at the Cancer Registry of Norway. Follow-up data until August 2013 was recorded, and end point was histologically confirmed CIN2, CIN3, ACIS or invasive carcinoma (CIN2+) within a three-year period following the index HPV.

**Results:** The index HPV was positive in 2756 /6059 women (45.5%). HPV genotyping revealed single infection in 1746/ 2756 cases (63.4%) and multiple infections with 2 or more genotypes in 884/2756 cases (32.1%). In 126 out of 2756 cases (4.6%) we were not able to detect the genotype (HPV X). HPV 16 was the most frequent genotype (35.0%), followed by HPV 31, 52, 18, 51, 45, 33, 56, 58, 68, 59 and 35. CIN2+ was confirmed by histology in 1191 / 2756 HPV test positive women (43.2%) and in 71/3303 HPV test negative women (2.1%). CIN2+ was significantly more often detected in women with multiple HPV infections compared to women with single HPV infection (53.4% and 39.9% respectively,  $p < 0.0001$ ). The predictive value for detecting CIN2+ for the different HPV genotypes will be presented.

25. Health behaviour predictors of non-participation in a mass screening programme for colon cancer in Finland

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(2) *Finnish Cancer Registry*

(3) *National Institute for Health and Welfare*

Colorectal cancer (CRC) screening has been shown to prevent 16% of CRC mortality in randomised trials. For an effective programme, participation in screening is essential. We studied various determinants of non-participation in the screening programme in Finland. Information on screening participation (2004-2011) was obtained from the Finnish Mass Screening Registry and information on health behaviour factors from the Finnish health behaviour surveys (1978-2002) from the National Institute for Health and Welfare. Information on demographic factors was received from Statistics Finland. Age, region, education, and marital and socioeconomic status were included in the analyses in addition to the health behaviour factors. Non-attendance was analysed with the Poisson regression as incidence rate ratios [IRR]. Out of persons invited to screening (n=160,762; participation rates 60% in men and 75% in women), 2,115 men and 2,349 women had also participated in the health behaviour survey. Non-married had higher likelihood of non-participation of screening than married both in men (IRR for never married 1.4, 95% confidence interval 1.1-1.7; divorced 1.4, 1.1-1.7) and in women (never married 1.8, 1.3-2.4; widowed 1.8, 1.2-2.7). Men with low education refused from screening more often (1.3, 1.1-1.7) than men with high education. Among women, blue collar workers (1.8, 1.1-2.9), retired women (1.9, 1.1-3.2) and other economically inactive women (2.2, 1.4-3.6) had higher risk of non-participation than upper white collar workers, and current smokers were more likely to non-participate (1.9, 1.5-2.5) than non-smokers. The selective participation should be taken into account when evaluating the effectiveness of CRC screening programme in Finland.

## 26. Sensitivity and maximal overdiagnosis in the randomized implementation of colorectal cancer screening in Finland

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Colorectal cancer screening was launched in Finland in September 2004 in a design where half of the 60-64-year old population was randomized to screening and half to controls. Screening started in 22 municipalities out of 444 and the coverage has since then increased to 45% of the entire target population. The objective was to study sensitivity of screening and evaluate the maximal overdiagnosis of screen detected cases. We also corrected the sensitivity estimate for selection bias. The material used comes from those randomised in 2005-2008 for the first time. Thus, the second and third invitation rounds were available for the entire group till end of 2012. Close to 95 000 men and women were invited with an uptake of 67.8% at the first and 70.0% at the second round. The number of CRC diagnosed at screen was 94 and 72 at the first and second round, and the estimated prevalence was 147/105 and 115/105, respectively. In all, 183 and 233 colorectal cancers were diagnosed in the control arm and 59 and 76 in non-attendees during the first and second round, respectively. The sensitivity was estimated at 32% at the first and 45% at the second round. The proportion of maximally over-detected cases was estimated at 68% at the first round and 25% at the second round. Sensitivity of the programme is high enough to support continuation of the programme. However, the potential of substantial overdiagnosis counterbalanced the finding. It is important to evaluate mortality from colorectal cancer as the final end point.

27. Risk of disability pension among rectal cancer survivors – a Swedish population-based study with a focus on clinical determinants

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**Background:** Improved survival among rectal cancer patients has resulted in increased attention towards long-term consequences of the disease and its treatment. A few previous studies report an increased risk of sick-leave and disability pension (DP) in colorectal cancer patients, but have not considered association with treatment and relapse.

**Material & Methods:** Using the Swedish Rectal Cancer Register, we identified 2599 rectal cancer patients aged 18-61 years at diagnosis 1995-2009, (stage I-III disease). Four matched population comparators per patient were also selected (N=8820). Information about DP as the main outcome was retrieved from Statistics Sweden, with end of follow-up Dec 31st 2013. Non-proportional and proportional hazard models were used to evaluate the annual and cumulative risks of DP and the association with demographic, clinical characteristics and treatment. In complementary analyses, only relapse-free follow-up time was considered.

**Results:** During a median follow-up of 6 years (range 0-19), survivors had a more than doubled risk of DP (HR=2.34, 95%CI 2.09, 2.61) compared with the population comparators. The risk remained 2-fold increased during follow-up without relapse (HR=2.20, 95%CI 1.96, 2.47). The annual risk of getting DP persisted until the tenth year after diagnosis. Among the patients only, pre-operative radiotherapy, complications leading to reoperation within 30 days and previous sick-leave were identified as determinants of DP risk, independently of relapse.

**Conclusion:** Rectal cancer survivors are at increased risk of permanent work disability long-term not explained by disease relapse. Preoperative radiotherapy and severe surgical complications, but not cancer stage, operation technique or other complications, enhanced DP risk.

# Session 5

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## 28. Assessing temporal trends in survival of acute myeloid leukemia patients using the loss in expectation of life

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**Background:** Acute myeloid leukaemia (AML) is an aggressive disease with a median age at diagnosis of 70 years. Previous studies have focused on presenting survival using relative survival ratios and cure proportions. Here, the loss in expectation of life (LEL) is presented as a useful alternative measure. The LEL is the difference between the life expectancy in the cancer population and a comparable group in the general population.

**Materials & Methods:** A cohort of 11595 AML patients diagnosed in Sweden between 1973 and 2011 was obtained from The Swedish Cancer Registry. The LEL was calculated by using flexible parametric models assuming cure after 10 years. One- and five-year conditional LEL were also calculated.

**Results:** The LEL decreased over year of diagnosis for all ages except the eldest patients whose LEL was approximately constant over time. The largest decrease in LEL was seen in younger patients; LEL for a 35-year old male diagnosed in 1975 was 40.2 (95% CI: 39.3-41.7) years and in 2011 was 16.0 (95% CI: 14.1-17.8) years. Both one- and five-year conditional LEL decreased over year of diagnosis for all patients with the greatest differences seen in the youngest patients. Five-year conditional LEL for all ages diagnosed in 2011 were below 2 years.

**Conclusion:** The LEL for patients has decreased over time with the youngest benefitting the most. The LEL provides information about the impact of a diagnosis for a single patient or a population and has a simpler, real-world interpretation.

## 29. Comparison of Different Approaches to Estimating Age Standardized Net Survival

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Age-standardised net survival provides an important population-based summary of cancer survival that appropriately accounts for differences in other-cause mortality rates and standardises the population age distribution to allow fair comparisons. Recently, there has been debate over the most appropriate method for estimating this quantity, with the traditional Ederer II approach being shown to have potential bias. There has been a move to using the new Pohar Perme estimator that is based on inverse probability of censoring weights. However, we feel that there is a move to changing practice without a full understanding of the implications. We have performed an extensive simulation study to evaluate a variety of methods to obtain age-standardised estimates of net survival, including the traditional Ederer II method, the new Pohar Perme method and model based methods. We have deliberately chosen simulation scenarios where we would expect the traditional approaches to have a theoretical bias. Our simulations demonstrate that even in relatively extreme scenarios there is negligible bias in age-standardized net survival when using the age-standardized Ederer II method, modelling with continuous age or using the Pohar Perme method. However, both the Ederer II and modelling approaches have some advantages over the Pohar Perme method in terms of greater precision, particularly for longer-term follow-up (10 and 15 years). Our results show that, when age-standardising, concern over large bias with commonly used methods is unfounded. We have also shown advantages in using the more traditional and modelling methods.

### 30. Long-term survival of cancer patients – what estimation method to use?

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**Background:** The classical methods for estimating net survival have been recommended to be replaced by the new method of Pohar Perme et al. that will be used in the international CONCORD-2 study. This recommendation has also been criticized, because it ignores the random variation, and therefore the new estimator can be very unstable especially in long-term survival. This simulation study compares the performance of the two widely used net survival methods (Pohar Perme and Ederer II) based on realistic simulation scenarios.

**Material & method:** The data from the Finnish Cancer Registry were used to create realistic settings for the simulation study. Excess mortality due to cancer itself was estimated for patients diagnosed with a selected set of cancer sites in 1982–1996 using a flexible mixture model. The optimal method was assessed on the basis of the bias, variance, mean square error and coverage proportion.

**Results:** Preliminary results show that the mean square error of the Pohar-Perme estimator was smaller than that of the Ederer II estimator in breast and prostate cancer where the numbers of patients were large and the patients had persistent excess mortality for the first 15 years after diagnosis. The internally age-standardized Ederer II estimator performed equally well as the Pohar-Perme estimator.

**Conclusion:** In any empirical data, estimates of net survival are subject to random error and the observed data are confounded by several factors the effect of which cannot be identified. An extensive simulation study is necessary for choosing the optimal method of net survival.

### 31. Comparing methods for estimating and predicting net survival

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**Background:** Cancer registries routinely report estimates of net survival for previous time periods where follow up time is complete, and predictions of net survival for recent time periods where follow up time is incomplete. The aim of this study is to compare various methods for estimating and predicting net survival.

**Material and methods:** Data from the Cancer Registry of Norway for 23 cancer sites was used. The unbiased estimator of Pohar-Perme (PP) was used to estimate the observed net survival up to 15 years after diagnosis, based on the cohort method. The adequacy of different estimators was studied by comparing the observed net survival to the average estimate based on 10 subsamples for each cancer site. The root mean squared error (RMSE) of each estimator was calculated. PP, Ederer2, age-standardized Ederer2 and a flexible parametric model (FPM) were compared. Predicted net survival was calculated using PP combined with period or two hybrid approaches, and using a FPM. Average absolute prediction errors were calculated.

**Results:** The RMSE of FPM were, in general, smaller than the RMSE of the other methods, indicating that FPM is useful for estimating net survival when complete follow up is available. Average prediction error across all sites was 1.74% using FPM, compared to 2.45% using the period approach. In particular, for 10 and 15 year predictions FPM was superior.

**Conclusions:** FPM should be considered by cancer registries for estimating net survival both for periods where follow up is complete and for periods where follow up is incomplete.

# Session 6

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32. Can indicators with target levels and a National assessment and evaluation increase adherence of National Guidelines in cancer care?

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**Background:** The Swedish National Board of Health and Welfare can offer professionals and decision-makers comprehensive National Guidelines for breast-, prostate-, and colon-rectal cancer care including; a revised body of scientific evidence with prioritized recommendations, indicators with target-levels and National assessment and evaluation. The aim is to establish good and equal health care in Sweden by increased adherence to the guidelines.

**Methods:** We used standardized, systematic and transparent processes to develop the guidelines, indicators with target-levels and National assessment and evaluation. These processes involve patients, professionals and decision-makers in the health care system.

**Results:** The guidelines in cancer care consist of 290 prioritized recommendations and 70 of them are highlighted for decision-makers, 42 indicators and the majority of them have target-levels. Even though our recommendations are distinct, our results show variances in regards to sex, age, socioeconomic and geographic distribution. For example, one recommendation of multidisciplinary team conferences showed great variances between county councils and socioeconomic factors. The target-level of this indicator is 100 percent and according to the evaluation almost 3000 more individuals would be eligible to this recommendation.

**Discussion:** National indicators with target-levels are a new approach. Our goal is that this would lead to more distinct recommendations. Is this a way to get improved adherence to the guidelines? We strongly recommend involving patients, professionals and decision-makers in the health care system when setting the target-levels. This is now a part of the Boards new strategy to improve adherence to the guidelines in Sweden.

33. Utilization of radiotherapy in Norway after implementation of The National Cancer Plan – a national population-based study

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**Background:** Major economic investments to increase radiotherapy (RT) capacity in Norway were decided in the 1997 National Cancer Plan (NCP). We aimed to estimate Norwegian utilization rates of RT, and describe corresponding time trends. Further to compare these with epidemiological- and evidence-based estimates of lifetime need for RT (EBEST) and with estimates of optimal RT rates in the NCP.

**Material and Methods:** Data from the Cancer Registry of Norway was used to identify all patients diagnosed with cancer, and/or treated by RT for cancer from 1997 to 2010. Radiotherapy utilization rates (RURs) were calculated as the proportion of cancer cases who received RT at least once within 1 year (RUR1Y) and within 5 years (RUR5Y) of diagnosis. The total number of radiotherapy treatment courses per incident cancer cases (TCI) was also calculated (all cancer sites combined). Actual RT rates were compared with corresponding estimates of optimal rates. Joinpoint regression was used to identify changes in trends and to estimate annual percentage change (APC) in RUR1Y and TCI rates.

**Results:** The RUR5Y (all sites) increased significantly to 29% in 2005, but still differed markedly from the Australian EBEST of 52%. All actual RUR5Ys, except in breast cancers, were markedly lower than EBESTs. The TCI increased significantly, reaching 42.5% in 2010, but was still lower than the 54% recommended in the NCP. Trends for RUR1Y (all sites) and TCI changed significantly in the study period.

**Conclusions:** RT utilization rates in Norway increased after the NCP was implemented, but are still considered suboptimal compared with appropriate levels.

34. Routine administrative data as additional cancer registry source on primary cancer treatment in Denmark.

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**Background:** The aim of this study was to explore the National Patient Administrative System (PAS) as an additional source to the cancer registry notification on primary cancer treatment one month before to 6 month after diagnosis of breast, lung, prostate, colon and rectum cancer.

**Materials and methods:** All incident cases of breast, lung, prostate, colon and rectal cancer in 2011 were identified in the Cancer Register and linked by the unique personal ID number to the PAS. Information on performed procedures from one month before to 6 month after date of diagnosis was extracted and considered part of the diagnostic work-up and primary cancer treatment.

**Results:** The proportion of patients undergoing treatment varied from 56-88% according to the PAS, highest for breast, colon and rectum and lowest for prostate cancer. The number and treatment modalities recorded per incident case had good compliance for diagnostic, surgery and radiation procedures for the given cancer, whereas for chemotherapy, hormone and biological treatment the number of registered procedures is lacking.

**Conclusions:** Registrations on diagnostic, surgical and radiation procedures recorded in PAS have a high validity in contrast to chemotherapy and hormone treatment. This is likely due to the substantial financial compensation for these procedures in the diagnostic related group system and that this is the initial therapeutic modalities most often completed within the first 6 month after diagnosis.

### 35. Completeness and comparability of register data at the Finnish Cancer Registry

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**Background:** Historical merits are not a guarantee on sustainability and the quality control should be continuous and systematic in cancer registration. We studied completeness and comparability of register data at the Finnish Cancer Registry (FCR) in comparison with other Nordic countries. The aim was to identify any outliers and to find possible underreported or misclassified cancer types for site-specific quality control studies in the future.

**Material & Methods:** Mortality:incidence –ratios (M:I ratios) (2008-2012) were plotted against 1-survival (based on diagnoses in 2003-2007) in Finland. For all countries M:I ratios (2008-2011) were derived from the NORDCAN database.

**Results:** Incident cases in the FCR comprise all malignant and in situ neoplasms, benign tumors of central nervous system and some tumor-like conditions. The coding in the FCR has followed standard codes set by the ICD-O-3 since 2008. The Finnish dataset for the period 2003-2012 comprised 296 915 incident cancer cases, excluding basal cell carcinomas, diagnosed among 265 192 individuals. The M:I ratio analyses between the Nordic countries showed reasonable concordance. It did, however, show differences between some cancer sites, the most prominent for eye cancer in males.

**Conclusions:** The quality of the mortality data is high in Finland and registration and coding routines in place at the FCR yields comparable data. It is important not only to adhere to international guidelines but also that in-house rules are discussed and delivered efficiently between Nordic cancer registries.

### 36. Evaluation of data quality in the National Prostate Cancer Register of Sweden

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**Background:** Cancer quality registers are used for quality assurance, benchmarking, and research and thus data quality is essential but to date there are little information on the validity of data in quality registers. We evaluated data quality in the National Prostate Cancer Register of Sweden (NPCR) in terms of timeliness, completeness, comparability, and validity.

**Material and Methods:** Timeliness and completeness was assessed by cross-linkage to the Swedish Cancer Register, and the Cause of Death Register. Comparability was assessed by comparing registration routines in NPCR with national and international guidelines and validity was evaluated by re-abstraction of data from medical charts for 731 men diagnosed in 2009.

**Results:** Within 3, 6, and 12 months after date of diagnosis, 46%, 77%, and 97% of cases had been reported to NPCR year 2012. The capture of NPCR was 96% of all Pca cases in the Cancer Register or diagnosed by death certificate only, and NPCR complied with national and international coding routines. Overall, the agreement between NPCR and re-abstracted data for all registered variables was high with a correlation between original registration and re-abstraction for S-PSA of 0.97, agreement for local clinical T stage of 83%, M stage 73%, and Gleason score on biopsies 97%. A higher number of prostatectomies had been registered in NPCR than in the Patient Register and over 95% of men registered with androgen deprivation therapy in NPCR had a corresponding filled prescription.

**Conclusion:** Data quality in NPCR was high in terms of timeliness, completeness, comparability, and validity.

### 37. Lag Time to Adverse Events after Radical Prostatectomy and Curative Radiotherapy

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**Background** Men with curatively treated, localized prostate cancer have a long life expectancy but data on long term complications to treatment are scarce.

**Materials and Methods** In the nationwide, population-based Prostate Cancer data Base Sweden (PCBaSe), we identified men who underwent radical prostatectomy (RP) or curative radiotherapy (RT) between 1997 and 2012, with date of radiotherapy reassessed in an audit. For each case five controls from the background population, matched for age and county of residence, had been identified. The National Patient Register was used to identify diagnostic and operative codes indicating adverse events up to twelve years after treatment. The incidence rate ratio of adverse events for men who received RP and RT relative to their matched controls was calculated and relative risk (RR) was calculated for RP vs RT with adjustment for tumour risk category, age, Charlson comorbidity index, educational level, and marital status.

**Results** At 3 years after treatment the risk of cystoscopy was lower after radiotherapy than after prostatectomy; RT vs RP RR 0.77, 95% CI 0.74-0.79 but 9-12 years after treatment the risk was higher after radiotherapy; RT vs RP RR 1.81, 95% CI 1.67-1.95. The same time trend was observed for transurethral procedures; RT vs RP RR 0.54, 95% CI 0.51-0.56 at 3 years and RR 1.88, 95% CI 1.66-2.09 at 9-12 years.

**Conclusions** Complications after RP mostly occurred within the first 3 years after surgery whereas complications after RT were more frequent at a later date after treatment.

# Session 7

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## 38. Cancer risk in Nordic firefighters

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**Background** Firefighters are exposed to a wide range of known and suspected carcinogens through their work. Exposures are intermittent and often relatively brief, but the heavy work load may increase inhalation and dermal uptake of toxic substances. The aim of the present study was to investigate cancer pattern in Nordic firefighters and compare results with studies from other regions.

**Material & methods** The cohort of firefighters (N=16 422) was identified from the Nordic Occupational Cancer (NOCCA) database which comprises occupational information for 15 million people from five Nordic countries followed up for cancer between 1961 and 2005. Standardized incidence ratios (SIRs) were computed using the cancer incidence rates in the national populations as references.

**Results** Overall, elevated risk of adenocarcinoma of the lung (SIR 1.29, 95 % confidence interval (CI) 1.02-1.60) and prostate cancer (SIR 1.13, CI 1.05-1.22) was seen. In the age group 30-49, there was an excess of prostate cancer (SIR 2.59, CI 1.34-4.52) and melanoma of the skin (SIR 1.62, CI 1.14-2.23). In the age group 70+ elevated risks were observed for non-melanoma skin cancer, multiple myeloma, adenocarcinoma of the lung, and mesothelioma. In contrast to previous studies, risk of testicular cancer was reduced (SIR 0.51, CI 0.23-0.98).

**Conclusions** Exposure from combustion products occurring during fire extinction may contribute to part of the risk elevations observed.

39. Factors Influencing Survival and Patient Selection for Treatment in Lung Cancer Patients from Norway in the Period 1980-2011.

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**Background:** Lung cancer is one of the most frequent and deadly cancer sites in the world. It is important to get a better understanding regarding factors which could explain the differences in survival. However, most studies regarding such factors for lung cancer survival are based on specific sub-group of lung cancer patients. We aim to study prognostic factors for selection to treatment (radiation therapy, surgery and other) and one year survival among the whole lung cancer population in a nation.

**Material and Methods:** We use all patients diagnosed with lung cancer in Norway between 1980 and 2011. Prognostic value of different host- and tumour specific factors like comorbidity, smoking status, socioeconomic status, morphology, topography and stage at diagnosis has been evaluated. In addition to nomograms, we used some measures to quantify the importance of the different prognostic factors. One of the measures we used is the average difference in the predicted one year survival probability with and without different variables. With logistic regression we analyse the relationship between treatment received and different explanatory variables, while by using Cox Proportional Hazard models we analyse the 1 year survival.

**Results:** Results for the different prognostic factors will be presented alongside a discussion about how to evaluate the importance of different prognostic factors both separately and in comparison to the other factors.

**Conclusion:** To be presented

40. Statistical cure and survival in Hodgkin lymphoma patients by clinical characteristics and treatment – a Swedish population-based study.

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**Background:** The prognosis of Hodgkin lymphoma has improved dramatically over the past decades due to improvements in staging, treatment and clinical management. Consequently, cure from the malignancy is now a realistic outcome among young patients with early stage disease. Our aim was to investigate how clinical determinants of the prognosis are associated with statistical cure among these patients.

**Material and methods:** This is a Swedish population-based study of 1218 patients diagnosed at ages 18-50 during 1992–2009, and followed through 31/12-2012. The patients were identified in the Swedish Cancer Register, and clinical information was obtained from the quality register for lymphomas. A review of medical records was done where clinical data was missing. Flexible parametric cure models were used to estimate cure proportions, C, and median survival times, MST, of uncured by stage (low/advanced), treatment (combinations of radiotherapy, RT, and chemotherapy cycles, CYT), sex and age.

**Results:** Statistical cure was reached within 10 years of follow-up. The cure proportions were significantly associated with stage, C(low):89% and C(advanced):98%, and treatment C(RT only):97%, C(1-4 CYT+RT):98%, C(5-8 CYT-RT):93%, C(5-8 CYT+RT):87%, but not with age at diagnosis or sex. The corresponding median survival times of the uncured (by stage) were MST(low):4.2 years and MST(advanced):4.1 years, respectively, and between 4.8-4.9 years irrespective of administered treatment. Among patients with a relapse (15%), statistical cure was not reached.

**Conclusions:** The cure proportions have remained relatively constant (and high) for the majority of the patients over the study period. Relapse remains the strongest risk factor against statistical cure.

41. The impact of cigarette smoking on survival from ovarian cancer: A pooled analysis of 20 case-control studies.

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**Background:** The prognostic impact of cigarette smoking on ovarian cancer survival has not been fully established. In a large pooled analysis, we investigated whether cigarette smoking is predictive for overall survival in women diagnosed with epithelial ovarian cancer and according to histological type.

**Methods:** We obtained data from 20 case-control studies of ovarian cancer, including a total of 14,531 women diagnosed with ovarian cancer. Cox proportional hazards models were used to estimate pooled hazards ratios (HRs) with 95 % confidence intervals (CI) for various cigarette smoking variables in relation to overall survival in women with ovarian cancer.

**Results:** Both former (HR=1.10, 95 % CI: 1.03-1.18) and current smokers (HR=1.19, 95 % CI: 1.09-1.29) had a poorer overall survival compared with women who had never smoked. In addition, poorer survival was associated with increasing number of cigarettes smoked per day (HR=1.01, 95 % CI: 1.00-1.03, per 5 cigarettes/day), longer duration of cigarette smoking (HR=1.02, 95 % CI: 1.00-1.05, per 5-year period), increasing age at smoking initiation (HR=1.01, 95 % CI: 1.00-1.02, per 1 year), and decreasing time since smoking cessation (HR=0.98, 95 % CI: 0.95-1.00, per 5-year period). Similar prognostic risk patterns were observed for the different histological types of ovarian cancer including serous, mucinous, endometrioid and clear-cell ovarian tumours.

**Conclusion:** Our results suggest that cigarette smoking is a negative prognostic factor for overall survival in women diagnosed with ovarian cancer. Consistent dose-response associations with multiple measures of cigarette smoking were observed. 237 words

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